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Episode 18: Lights, Camera, Action – and Accessibility: Part 1 July 10, 2022

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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 all together, thanks for joining. Now let's get started.

Mindy Henderson: Today's guest is Leah Zelaya. Born with a rare form of neuromuscular disease, Leah faced a host of challenges, including medical claims that she would possibly never walk. In spite of these obstacles, Leah learned to believe in her abilities. In 2008, through strenuous physical therapy, she began to walk with bilateral leg bracing and a walker. Later in that year, she traded her walker for a pair of forearm crutches that improved her independent ambulation. Leah has taken that determination and applied it to sports and the arts. Leah is a dancer, cyclist, actor, model, and advocate for the community of individuals with disabilities.

Mindy Henderson: Her list of credits is far too long to read, but some of her accomplishments include she recently made her debut as an actress in Universal Pictures movie production called Marry Me starring Jennifer Lopez and Owen Wilson. In 2020, she was enrolled in Open Style Lab's summer program, where she collaborated with Open Style fellows and MDA members to create the easy zip, a functional hand tool that assists people with their zippers. She also in 2020, walked in the

New York Fashion Week, which is super cool. I'm totally jealous. She entered her first adaptive skiing competition through the Adaptive Sports Foundation called the Hartman Race in which she won first place bi-ski girls division. And since 2016, Leah has served as an ambassador for the MDA and has gone to our nation's capital to speak to senators and Congress representatives of New York state.

Mindy Henderson: I'm exhausted, Leah, and I didn't even mention everything that you've done. Thank you so much for being here.

Leah Zelaya: Thank you for having me.

Mindy Henderson: You are absolutely amazing. You and I had a chance to talk a little bit last week and I am just blown away by how accomplished you are. You are 14, is that right?

Leah Zelaya: Yes.

Mindy Henderson: Okay. You've accomplished more than most 60 year olds have accomplished, so you should be very, very proud of yourself. Would you mind just starting out by telling us a little bit about your diagnosis and how it affects your daily life?

Leah Zelaya: Yeah, sure. So I have a rare form of neuromuscular disease called scapuloperoneal spinal muscular atrophy, so it causes my muscles to atrophy and it weakens and limits my ability to walk. So I don't really think about how it affects my daily life so much because I'm so used to living with my condition, but if I had to, it would be my hands. My hands do weaken a little bit and I walk with braces, but I have a wheelchair if I'm tired that I can use and I have crutches as well.

Mindy Henderson: Got it. That is fantastic, and like I said, you do so many different things. You act, you dance, you model, you cycle, you're a designer. Have I forgotten anything? Is there anything else that you do?

Leah Zelaya: Yes, I'm a skier and I'm also a cyclist as well.

Mindy Henderson: Awesome. That is so, so cool. Let's start with your acting. Let's talk about that first. Like I said, you were recently in the movie Marry Me with none other than Jennifer Lopez and Owen Wilson. How did you start acting?

Leah Zelaya: So I actually started through Easter Seal's Disability Film Challenge. Nick [inaudible], the head director, was actually the one who referred me for the role of Mary.

Mindy Henderson: That's very cool. And do you take acting classes? How does one actually learn to act?

Leah Zelaya: Yes, I've been taking acting classes, private acting classes. I've been taking them for quite a while. I think one learns how to act is through time and of course,

dedication, but the main thing is obviously learning your role and the character you're going to be. But for me, what helps me is learning how to become that character, but I think when I dedicate my time to it, I can become better at acting.

Mindy Henderson: That's really great. So I asked you this question last week when we talked, because again, not that I have any talent for acting, but I think all the time when I watch movies about these intense scenes that I see actors film, and I think about being the person and having cameras and people around them and having to focus on who they're supposed to be and what they're supposed to be doing. Is that weird for you? Or how do you get used to that?

Leah Zelaya: Well, it was my first time so it was a little weird, but I think once you start going on set where you kind of get more comfortable in that area, it is weird a little, but it also ... You become a lot more comfortable when you do it a lot.

Mindy Henderson: Yeah. And what was the audition like for the movie? Was there an audition?

Leah Zelaya: Yes, so there was an audition and that was my first ever audition and I was so nervous. I didn't know how to act. I didn't know a lot of things. Thank God I had my mom there, because if I didn't have my mom I would've just been all over the place, but I was nervous and I was scared and going in I thought I wasn't going to do so well, and I went in. They actually make you feel so comfortable and they're so sweet and they just give you this confidence that you can do this. And after that, it was just like smooth sailing from there.

Mindy Henderson: Nice. Were you reading lines with anybody or was it where you just went in and read a section of your own part? How did it work?

Leah Zelaya: So I did ... They did give me lines to memorize to read, so I did memorize those lines and bring it in. I read with them. I did.

Mindy Henderson: Okay, nice. What was it like, I have to ask, working with Jennifer Lopez and Owen Wilson?

Leah Zelaya: Working with Jennifer Lopez and Owen Wilson, and also I worked with Maluma. That was really crazy because that was my first time ever doing a movie, and a lot of people when they do is they get to work with such big stars.

Mindy Henderson: Right.

Leah Zelaya: And such [inaudible] people, and I think that was just such a shock, but I was also so blessed and grateful that I was able to have that experience, and I will honestly never forget that because that is something that I will keep close to my heart and I will look back when I get older and be like, "Wow, I was in a movie with JLo and Wilson and Maluma. That's crazy."

Mindy Henderson: Definitely. Definitely. Do you have a favorite story of working with any of them?

Leah Zelaya: I actually have a lot of stories with all of them. What was cool is that I go to dance with JLo. That was something really awesome because a lot of people want to dance with her and I got to dance with her because I'm a dancer and she's a dancer, so I got to dance side by side with her and I got to learn a little from her. Oh, and she was still cool and so awesome. And at the end of ... Actually, last year, I think it was filming for me and he actually came out and he gave me a hug and he [inaudible]. That was really special. And then from Maluma, the first day I filmed with him, he actually saw me and I went to go see hi, and he actually gave me a kiss on my forehead so that was like my first kiss outside of my household.

Mindy Henderson: Oh.

Leah Zelaya: And I got to have that with Maluma, so that's like ...

Mindy Henderson: Not bad.

Leah Zelaya: Not at all.

Mindy Henderson: That is something to remember. That's really nice. So to kind of take on a little bit of a more serious note, we hear a lot about needing more positive representation of individuals with disabilities in the media, in Hollywood, on television, in movies, all of that. Did you tell me that this part was actually created for you?

Leah Zelaya: Yes, it was actually created for me. The casting director was looking for someone to represent the disabled community and this was my first time acting and the director had created this role for me, and what was crazy about it, she used my name Leah. So my name is in a Universal Picture and it's Leah, it's my name, and I just think that's so incredible.

Mindy Henderson: That's amazing. It's so flattering. I mean, they must have absolutely thought the world of you and you're ... I mean, you're such a special person. You're so likable. I can ... I get why they did it, but it must have just been really special for you. So do you think that we're making progress in Hollywood in terms of inclusion of people with disabilities? Is there anything else that you would like to see happen?

Leah Zelaya: So honestly I do think that there is more of an inclusion in Hollywood in the disabled community because when I was younger, I didn't see a lot. Normally you wouldn't see it in commercials, but now you see it in more commercials, you see it in more movies, but I think that in some parts in Hollywood you do need more of the disabled community. I would see movies with people who are not disabled take roles like that, and I just think yes, you're acting, but you could be the best actor in the world and it still won't be believable because you do not know how to live with that disability. And I think it would be more believable if you had a person who was disabled being in that role. And I would believe it more and I think we need more of that because I think that's more beautiful than having someone who does not have a disability take that role.

Mindy Henderson: Very well said. Very well said. All right, I'm going to switch gears and I want to ask you about fashion. I love movies and things, but I really love fashion. I love shoes. I love clothes. All the things. Tell me about the zipper that you created.

Leah Zelaya: So I actually collaborated with Open Style Lab, another non-for-profit organization. I collaborated with their Open Style Lab fellows and MDA collaborators in December 2020, and we made an easy zip and basically the easy zip is something to help you zipper anything. It could be a bag, shoe, it could be a coat, a sweater, and it just makes it accessible and easy for you to zip up, and it's really an amazing tool.

Mindy Henderson: That's awesome. And so you can ... It's like a separate piece, right? That you can sort of attach to any zipper. That's amazing. And you also told me it's customizable, right?

Leah Zelaya: So it is customizable. You can make it into any design you want, you could color it, you can [inaudible] anything you want. It's a really awesome tool. There's not a lot of tools out there like that you could customize the way you want it to, so that's what the most intriguing thing for me is about it.

Mindy Henderson: Yeah, it looks amazing. I've seen pictures of it and it looks so smart. Do you see yourself designing more clothing or accessories in the future?

Leah Zelaya: I definitely see myself designing a lot more things. I want to design shoes for people who wear braces like me because I know when I was younger I used to get so frustrated because I couldn't get the type of shoe I wanted because it didn't fit my brace. But with that thought of how I was when I was younger, I would like to think of other people who have braces like me and possibly go through that still now that I could possibly help them create a nice shoe. If you're going out somewhere nice, you don't want to go around wearing sneakers, you want to look like ... Wear a nice heel or something. I would like to design something like that for people with braces.

Mindy Henderson: I love that. And you know what I really like about you is that you see a problem and you set out to fix it. You're such a solution oriented person, it's fantastic. So I'm curious, have you started to see more shoes that work with your braces and things? Or is it still an area where there's just not much?

Leah Zelaya: No, I do. I actually wear Billy Goat shoes and they're actually awesome because they have ones for my braces that fit, but I do use Billy Goat footwear and they're really great shoes. Actually my brace, where I go to get my braces, we told him about these shoes and he tells everyone now about these shoes and [inaudible] now everyone who has braces can have a shoe that can fit them. So I [inaudible], but I would love to design my own as well.

Mindy Henderson: Nice. Very cool. So let's talk about your dancing. I mean, there's so much to talk about. Tell me about your dancing and how you got started.

Leah Zelaya: Yeah, I actually started when I was six years old with Dancing Dreams. I've been dancing for around 10 years now, which is crazy to think about because time just goes so fast. So I have an awesome dance teacher named Joann Ferrara and she teaches people, children and teenagers with special needs, how to dance adaptively. And it's really a beautiful thing to see because you might have a child or you might know a person or you might be that person who wants to dance, but not a lot of places have a place for you to go because they won't accept you and say, "Oh, you can do that." But this place actually welcomes you as open arms and shows you that you can do whatever you want to, and if it's your heart to dance, you can dance. And I've danced on Lincoln Center with them, I've danced in a lot of places with them, and I'm just so grateful to be part of such an amazing program.

Mindy Henderson: And tell me the name of it one more time.

Leah Zelaya: Dancing Dreams.

Mindy Henderson: Okay, cool. We're going to put that in the show notes too, so that if there are other dancers out there or aspiring dancers, they can know where to look as well. So again, you do so many things. Do you have a favorite? If you could only do one for the rest of your life, which one would it be? I'm going to make it really hard for you.

Leah Zelaya: I know, that's like super hard. I haven't really thought about what's my favorite. I love to do them all. Honestly, everything I do I love, but if I had to pick a favorite, it possibly would be dance. I've always been passionate about dance because it goes with music and I love music, so pairing those two things together is really my passion. But I do love to do everything that I'm doing now.

Mindy Henderson: That's really cool. Actually, I really like that you said that because I was having a conversation with someone else the other day and I feel like singing and dancing are the two things that no matter what can put you in a good mood. If you're feeling down about something, singing your favorite song at the top of your lungs and just belting it out, or just dancing it out and having a big old dance party, those two things just always put you in a good mood.

Leah Zelaya: Yeah, they do.

Mindy Henderson: So is it ever hard with your ... I would think that it would be, it might be a silly question, but with your physical limitations, do you get tired or do you have to modify what you're doing at all so that you can do it all?

Leah Zelaya: Yeah, like I said before, [inaudible] my condition for a long time, so sometimes I think I do have to modify certain things, but most of the time I think I get so used to it that I don't really have to modify so many things because I already know how to do it in my own way. So I don't really have to modify too many things because I already know how to do it.

Mindy Henderson: You've figured out how to make it work for you.

Leah Zelaya: Yeah.

Mindy Henderson: Yeah. Also, I feel like you're just a little Energizer bunny. I feel like you've just got energy that never quits. So what goals do you have for yourself in the future?

Leah Zelaya: Everything I'm doing now I think I want to continue in the future because I love everything I do now because I'm advocating in everything I do. It could be to dance and acting. In everything I do, I'm doing it for others, I'm not doing it for myself, and I think being a voice for others is what I'm willing to do. But I would love to go out to different countries and be a voice for others because I'm very blessed to have things I have and I know that other children, other people in different countries don't have what I have and I would love to be a voice for them and to help them and give them a level of confidence. And I think that's what I really would want to do going into the future.

Mindy Henderson: That's fantastic, and you would be such a good example to people around the world of what's possible because I feel like with you and listening to you talk, you really see the possibilities instead of the limitations, which is so great. What about like right after you finish high school, do you want to just hit the dancing and the acting and the everything full time or what's the plan?

Leah Zelaya: I'd actually like to. I know that sounds a little crazy, but I would actually like to. I don't really know what it's going to be like for me in the future. I think I'm going to focus on what I'm doing now, but if I had to, I would want to do everything that I'm doing now in the future.

Mindy Henderson: That's so great. That's so great. So for anyone else that might be out there listening, if we've got other kids out there that want to act or dance or model, and maybe don't quite know how to get started or how to find good people to work with and things like that, what would your advice be to them?

Leah Zelaya: Well, if you want to do these things, I think that you should do these things. And if this is your heart, you should not let anyone stop you. But if you want to be an actor, there's the Easter Seals Disability Film Challenge. And if you're a dancer in New York, we have Dancing Dreams, and these type of places are the ones that will, I think, build your confidence if feel like you're in a shell because I know I was in a shell at first and I was always nervous and I didn't know if I could do certain things. But I think if you get involved with these programs and you meet other kids who might have similar conditions to you, I think you would start to grow and then be a voice for others. So I think these type of places are important for you, but also for others out there.

Mindy Henderson: Great advice. That's so good, and I think it's a perfect note to end on. I just want to thank you so much for spending a little bit of your day with me. I know how busy you are and I just have really enjoyed getting to know you. You're such an impressive young woman and I know that you're going to go on to do amazing things.

Leah Zelaya: Thank you so much.

Mindy Henderson: Thank you.

Mindy Henderson: Thank you for listening. For more information about the guests you heard from today, go check them out at [MDA.org/podcast](https://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](https://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.