

# Quest

## PODCAST



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### **Episode 19: Lights, Camera, Action – and Accessibility: Part 2 July 12, 2022**

(Music playing)

Mindy H.: 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.

Mindy H.: James Ian is a singer, songwriter, multi-instrumentalist, actor, and writer. He lives with spinal muscular atrophy type three, and is a passionate advocate for authentic representation of disabled actors in TV, film, and other media. James's music is featured on the iHeartRadio website, his filmography includes several movies and commercials, TV series and documentaries, including *The Allnighter*, *Pugsley*, *Kimboo and Kids*, and *Inner Warrior*. James grew up in Maryland and attended college and law school in Washington, DC, and now resides in Los Angeles.

Mindy H.: James, thank you so much for being here. I'm so excited to talk to you.

James Ian: Thank you, Mindy, for having me. Same here, really great to talk to you, looking forward to it.

Mindy H.: Awesome. Well, would you mind starting out a little bit, I should say, I've also got SMA. I'm SMA type two, so different type than you. Do you mind just talking a little bit about your diagnosis and how it affects your daily life?

James Ian: Sure. Yeah. Like you said, Mindy, you're familiar and even though we have different types, I'm pretty sure we have some of the same kind of physical manifestations of it. For me, I think they often call the type three kind of later onset. I had kind of exhibited symptoms, I think, throughout my childhood, but it wasn't noticeable enough to the level where someone was like, Hey, what's going on? Is there any [inaudible] reason that you were running this way, or doing whatever? I played sports and stuff. I had really bad asthma as a kid so I ran slower than my teammates and classmates and all that stuff, but my doctors and everyone else just thought it was because of my asthma. And they thought as I would get older, I'd kind of grow out of the asthma and be able to run better and do those things.

James Ian: And so when I was about 14, when I started to kind of hit puberty more. I started to fall a lot more and trip. And at that point in time I could get up on my own and I was using stairs and all that stuff and it still, I don't think, was really noticeable, but one day my parents noticed that when I got up from a chair, I could not do it without using my hands to push off of the seat. And it wasn't even a major thing, it was just I just give a quick little push and I could lift myself up just fine. I just couldn't do it without that. And so they saw that I couldn't do it. And so they took me to doctors, and I got the incorrect diagnosis of muscular dystrophy initially, which is fairly common in the SMA community on that kind of diagnosis journey. And then after second opinions, they did several tests and found out that I did have spinal muscular atrophy, but even at that time, there was not a lot... Obviously, they know more today about it than they did.

Mindy H.: Right. How old were you when you got that SMA? Were you 15, 16?

James Ian: Well, I was 14 going on 15. Yeah.

Mindy H.: Oh, you were 14. Okay.

James Ian: Yeah.

Mindy H.: Okay.

James Ian: My 25th diagnosis anniversary was on June 9th.

Mindy H.: Oh, well, happy anniversary. I don't know that that's appropriate, but-

James Ian: Yeah, no, no. I call it my SMAniversary.

Mindy H.: I love that. That's awesome. Tell me, being 14, I was diagnosed when I was 15 months old.

James Ian: Okay.

Mindy H.: And so it was kind of up to my parents to really live that journey, unfortunately and deal with the information. What was it like for you being 14, almost 15, and to hear that all of a sudden, you had this health condition?

James Ian: It was scary. I mean, my parents, for sure, at that age I didn't fully understand everything. All I knew was the body that I was living in, and so it didn't really feel it affected me that much. I mean it did, but like I said, I was running and stuff, and I was just kind of slower than my non-disabled peers. For me, it was kind of closure because I had felt for a while that something... I knew that I was different from my friends and stuff when I did sports and stuff. And I was like, why can I not jump as high [inaudible]?

Mindy H.: Yeah.

James Ian: Something feels different to me. And so in that way, I was like, oh, that's the answer, but then I think, like I said, my parents were very devastated and really upset and were kind of worried about the life ahead. For me, I was like, we'll just kind of see when we get there because right now, I've been doing all the things that I pretty much wanted to do. I don't really know.

Mindy H.: Right.

James Ian: It was just more of a closure thing in that regard of unanswered questions, but then it was like, I don't know what it's going to be like in 20 years or whatever.

Mindy H.: Mm-hmm (affirmative). And what has it been like? Since a bit of time has passed-

James Ian: Yeah.

Mindy H.: What's the journey been like for you? I mean, you seem like such an upbeat, positive guy. Have you been able to roll with it pretty well and stay positive? Have there been difficult moments?

James Ian: Yeah. I mean, definitely. In high school I grew a lot taller and so it-

Mindy H.: Right.

James Ian: Started to hit me harder. End of junior year, senior year I was falling more and I noticed it was a little bit more difficult to kind of go upstairs or do whatever. And

so that was hard. It was a shock to the system. And so when I got to college I went to school on, we call it the Hilltop. It was a lot of walking, a lot of uphill.

Mindy H.: Yep.

James Ian: And so I ended up taking the second semester of my freshman year off because my body couldn't handle it and I needed to adjust. And so that was hard, during those years, I became very much withdrawn.

Mindy H.: Yeah.

James Ian: I was very much a people person all my life. And-

Mindy H.: Yeah.

James Ian: I was just like, I don't want to deal with this, I don't want to talk about it. I tried to hide my SMA because I could for a long time. I was like, I don't want to engage with people. I'm just going to stay in my room or do whatever. And then that second semester I went home. No one saw me. And it was hard to do with mentally, like [inaudible]-

Mindy H.: Yeah.

James Ian: All that stuff. And so when I came back to school the following year, it was still an adjustment, but then I kind of had this epiphany of starting to tell my story and stuff.

Mindy H.: Yeah.

James Ian: I felt a lot better. People were very accepting for the most part. I started to have a great social life in college. And so I was really happy and enjoying it. And when I started to just learn my body and I knew what I needed to do, I felt better physically.

Mindy H.: Yeah.

James Ian: [Inaudible] years where I felt really good physically, it's just in the last, I would say the last eight or nine years, when I fall, I can't get up on my own anymore. And so I have really started to see the progression of SMA really start to take effect in that time period.

Mindy H.: Yeah.

James Ian: It's been tough, I have my days. I mean, I only know what I know. And so the weird thing I will say is it is very strange to be able to do things that I could a

certain point of time, just a number of years ago, and then not be able to do them-

Mindy H.: Yeah.

James Ian: That is wild. Mentally, for me, I'm like, I can't believe that I can't do this and I could do this however many years ago. That's been the tough part and it's like, you're always kind of adjusting to it. You're adjusting to a changing body all the time.

Mindy H.: Mm-hmm (affirmative).

James Ian: That's been tough. I am kind of upbeat, like you said, and that's just because I think I have so many things on my plate that it's hard to kind of dwell on it.

Mindy H.: Right. It's true.

James Ian: But I do have my days of depression and feeling really down about it and I get angry about it too.

Mindy H.: Yeah.

James Ian: Because you're angry that I can't do what I did, whatever, however many days or months or years ago it was. And so, that's hard, but it's ups and downs with anything with life, I think, but I will say for me, to see the progression in real time into... That is hard to deal with at times and that's what I'm really kind of coming to grips with at the present time-

Mindy H.: Right.

James Ian: That might be my big thing.

Mindy H.: Right. And yeah. And you describe it so well. I mean, I love the way that you kind of described it as it's sort of an ever changing body that you're living in and it's so true. And that's hard when you think you got a handle on it and then something else changes.

James Ian: Yeah.

Mindy H.: But I think like you said, it's healthy to feel angry sometimes and it's healthy to feel down sometimes. And we have to give the space to all of those emotions, I think. Otherwise, it's going to go somewhere. And so I think we have to honor it and give it time to work its way through us.

James Ian: Right. Part of the human condition.

Mindy H.: It is, it really is. And you talked about having a lot on your plate and I want to get into that because you are a total Renaissance man. You act, you sing, you play instruments. How do you even describe yourself? Are you more of an actor, are you a musician? How do you label yourself? Not that we need labels, but...

James Ian: Yeah, that's a really good question, Mindy. It is hard because I love just creative expression. I love creating things.

Mindy H.: Mm-hmm (affirmative).

James Ian: I love being an artist. And so I honestly derive kind of equal amount of joy, I think, from both. They kind of allowed me to do, oh, it comes from the same place, but they're a little different. And so I think it kind of depends on the day, but I think I'm always both, and I'm always in both spaces, to be honest. I'm either always auditioning or working all in some sort of acting project and I'm always doing something music related. I just kind of say artist, but I love both and I also would think both are really important from a disability representation-

Mindy H.: Yes.

James Ian: Perspective because they're not there in both of those kind of fields.

Mindy H.: Absolutely, absolutely. And I also kind of wanted to throw out there, just the idea that you have these passions that you're getting to live into and make such a prominent part of your life. And I think that's another thing that I would say about living with disability or illness is that if you can look for the things in your life that you're truly, truly passionate about and do those things in whatever capacity you can, just incorporating those things into your life at all, it makes, I mean, a night and day difference. If you've got stuff that lights you up when you wake up in the morning, that's huge.

James Ian: Yes. I totally agree. It's what you do, what makes you tick and that you're a passionate about. And I heard, I forgot where I heard this and I forgot who said it, but I heard this thing that was like, happiness is having things to look forward to.

Mindy H.: Yeah.

James Ian: And that kind of hit me and I do. These projects and stuff, whatever they might be, no matter what it is, no matter what the scale is, if it's something that not many people will see or tons of people will see, I just look forward to all of that and I just get excited about everything.

Mindy H.: That's so great. I have to ask what instruments do you play?

James Ian: Yeah. I play piano, guitar, drums, bass. And then I do like auxiliary percussion stuff, bongos and stuff-

Mindy H.: Oh, wow.

James Ian: Like that. And then I'm a vocalist, as... Vocalist has been the primary thing-

Mindy H.: Yeah.

James Ian: To me, but throughout the years, I've learned those just to supplement my live stuff. But my first introduction to music was my parents got me into piano lessons when I was five years old.

Mindy H.: Okay. Same.

James Ian: One of those... Yeah.

Mindy H.: Yeah. Yeah. In fact, I also wanted to be a singer and have spent time pursuing music over the course of my life. More of a country music vibe so not sure if that's what you're into, but when I told my parents that I wanted to sing, I mean, they were for it in kind of a sing in the church choir kind of way. And I don't think they thought it was something I would ever want to pursue professionally.

James Ian: Yep.

Mindy H.: And later on when I kind of did want to pursue it professionally, they freaked out a little bit, because it's such a risky career path and all of that. How did your parents react when you told them that you wanted to sing and act?

James Ian: They were fully supportive. The singing came a little bit later. I was singing from as soon as I could talk pretty much-

Mindy H.: Yeah.

James Ian: But when I really wanted to do it, I was in middle school and stuff and they were really supportive, but the acting thing, my mom when I was, I think I did my first acting thing at seven or eight, maybe eight. And she kind of, I think, saw that I was interested in it and was like, Hey, would you want to do this? And so we went out and got an agent and I started auditioning and stuff.

Mindy H.: Wow.

James Ian: She loved that, but my parents have been really, I mean, extremely supportive. Me and my siblings, they always stressed the importance of academics. We all went to very good schools and falling into the spot, very good grades. And so that was for sure a priority, but they all supported our passions. I have a younger

sister that's a singer and actor as well. She went to Berkeley College of Music, she's phenomenal singer.

Mindy H.: Oh sure.

James Ian: They really pushed... They were supportive of that. My other sister went to UVA for fashion design and art.

Mindy H.: Wow.

James Ian: [Inaudible] that. My brother was a very good visual artist. They always supported us. For me, it was really cool because some of the instruments, I didn't really pick up drums and guitar until college and beyond that. And so I had a drum kit in my basement during the summers at, at home and no one ever got mad for me making a ton of noise and [inaudible] drum.

Mindy H.: Yeah.

James Ian: And my parents were always like, my dad like, you're improvement sounds great. They never were like, don't play the drums. I'd play for hours, they never stopped. And then when I was in law school, the band that I was in, we started to get more local recognition. We started to travel and stuff and play a lot of cool shows. And my parents would always ask me, they knew I was in law school and they'd be like, law school was almost an afterthought. They'd be like, how was the show this weekend? What was the crew?

Mindy H.: Nice.

James Ian: They knew that it was something important to me so they just pushed me. They were like, if you like this, you do it. And I'm really grateful for that because like you said, your parents freaked out, lots of my friends who had any sort of whatever, their parents were discouraged.

Mindy H.: Yeah, absolutely. Absolutely. I want to take you back to law school for just a second, because I did kind of gloss over that in the-

James Ian: Yeah.

Mindy H.: Intro, but did you ever pursue law or work in law at all?

James Ian: Yeah, so I did. I don't practice. I did get my law degree and I do disability rights kind of work. I split my coursework in law school between corporate law and then the disability advocacy, just human rights, social justice. I took a number of courses in that area.

Mindy H.: Oh, I love it.



James Ian: I did work in the legal field. I was a paralegal right after college and I had done legal support stuff in that. But then just the music stuff was so important to me.

Mindy H.: Got it.

James Ian: And when I graduated, I graduated in the recession essentially. It was really tough to do that and it was hard studying for the Bar from a financial perspective.

Mindy H.: Yeah.

James Ian: My heart really wasn't in it. And so it was just like, I was way more focused on the art stuff than legal.

Mindy H.: Yeah. Well, clearly that worked out for you.

James Ian: Yeah. Yeah. I did do some stuff in that realm and I got a taste of it and a little experience there.

Mindy H.: Mm-hmm (affirmative).

James Ian: Always in the back pocket if I ever wanted to really go after it, but it's not where my heart...

Mindy H.: Yeah.

James Ian: My heart hasn't been there for a period of time.

Mindy H.: Yeah. Well that's awesome. I think that it's great that your parents gave you that kind of upbringing and that they were so supportive of what you really, really loved.

James Ian: Yeah.

Mindy H.: That's fantastic. I want to talk about the song Spaces for a second.

James Ian: Sure. Yeah.

Mindy H.: Because I looked on YouTube this morning and the video for this song, you probably know this, but the video has over 744,000 views.

James Ian: Yeah.

Mindy H.: Are you aware?

James Ian: Yeah. Yeah. It's so cool. It's-

Mindy H.: That blew my mind. I love this song. I have not been able to get it out of my head since I listened to it again this morning. Do you mind telling us the backstory on this song and how it was created?

James Ian: No. No, not at all. Yeah. It's a really cool partnership. Genentech, in partnership with myself and 10 other members from the SMA community, they wanted to really highlight just the lives of people with SMA. They have a program called SMA my Way, just talking about everyone's lives and just all the cool things that people in our community are doing, such as yourself. I know that you're an author, you're doing all these things and that stuff is not really talked about a lot. It can be very SMA diagnosis kind of clinical focused.

Mindy H.: Yeah.

James Ian: They did this program and they wanted to just kind of highlight that a lot of the people in the community feel that we are not represented in entertainment or whatever it might be. And so we're doing all these great things, they wanted to highlight that, and they thought that a good way to do it was through song. They brought myself together with the other folks and we just kind of sat down and had a brainstorm about the ideas and lyrics that we wanted to convey in the song.

Mindy H.: Mm-hmm (affirmative).

James Ian: And so then from there, from that brainstorm, I kind of boiled everything down into a rough draft of what we wanted to say. Really, really, really wanted to focus on it not being so, oh, you're inspirational solely based on the fact that you have SMA and all this. Really wanted to not fall into kind of those tropes. And then I worked with two music industry execs. One, he's a three time Grammy nominated producer, he actually works with lots of big country artists.

Mindy H.: Oh, okay.

James Ian: And so that was cool. Then the other one, he's a music industry executive, very high ranking at Universal Music.

Mindy H.: Uh-huh (affirmative).

James Ian: And so we've sat down, just refined it and made it into what Spaces currently is in terms of lyrics and all that stuff.

Mindy H.: Yeah.

James Ian: They had input about they know what is successful on radio and stuff. That input was very, very valuable.

Mindy H.: Yeah.

James Ian: That's where Spaces came from. And then the music video was, Dominic Evans spearheaded that, Dominic has SMA type three as well.

Mindy H.: Uh-huh (affirmative).

James Ian: Dominic, I thought, did an incredible job with the video, just-

Mindy H.: Yeah.

James Ian: What he wanted to say and I thought he did it in such a tasteful and a beautiful way. And so got to give credit to Dominic there, with obviously a team of also really good creative professionals.

Mindy H.: Right.

James Ian: Who are doing amazing, incredible work in Hollywood and that's where all the stuff came from it and it's just been a really amazing ride and experience.

Mindy H.: I bet. How long did it take, start to finish?

James Ian: Honestly, Mindy, it didn't take that long.

Mindy H.: Really?

James Ian: Yeah. It happened last summer. We did the brainstorm in, I think, early July.

Mindy H.: Uh-huh (affirmative).

James Ian: And after the brainstorm, that was a Thursday or something. I think by that Sunday, I had finished the rough draft. Then I met with Barry and Tom, who were the professionals, Wednesday or Thursday. And then I think by that weekend, this final song was done. It was honestly 10 day process maybe to have the-

Mindy H.: How?

James Ian: Song done.

Mindy H.: Uh-huh (affirmative).

James Ian: And then the video was just kind of being worked once the lyrics were finalized, but the video worked, but I don't even think that was a long process. And then we did the song and the video back to back on a Thursday and Friday in the middle of September. And then it was pretty much done, published, did the edits and all that stuff in studio and all that stuff and it was done.

Mindy H.: Wow.

James Ian: It was not a long process, and I think the project kind of was conceived spring of last year.

Mindy H.: Wow. That's amazing. And I have to comment because you mentioned the whole inspiration factor and all of that and the whole thing is so well done and tasteful, like you said, and when you watch this thing, you could be talking about anybody. And what I loved so much about it is that in my sort of humble interpretation, it's about seeing potential in [inaudible].

James Ian: Yeah.

Mindy H.: And in fact, my favorite line from the song is "I'm so much more than what you see and what you bargained for." I love that. It still gives me goosebumps.

James Ian: I love that. Yeah. I'm glad that you said that Mindy, that was definitely one of the things... I mean, it was created by the SMA community for the disability community and for non-disabled people too, everyone outside of that. I think it is really relatable. I've gotten feedback from people who don't have disabilities at all and they tell me what this song means to them and there's-

Mindy H.: Yeah.

James Ian: Nothing to do with disability for them. We did want it to be very broad and just relatable.

Mindy H.: Absolutely. Yeah. And for so many of us living with disabilities, we are underestimated on a regular basis because of our physical limitations and it's so important for the rest of the world to realize what they should see when they look at not just people with disabilities, but anyone, like you said, is the potential and not the limitations. I do want to ask you, how does your diagnosis of SMA factor into your singing, playing instruments? And for me, again, we have a different type of SMA, but I've got a slightly compromised respiratory situation and so, is that anything that presents a challenge at all in what you do?

James Ian: From the instrumental side of things, it does. Like I said, as time has gone on, I've gotten weaker. When I was in college, I was at a jam jazz fusion band, I was the drummer. And we would do three and four hour sets, and I could pretty much do it. We would take little breaks here and there, but I mean, we would do songs that were 20, 30 minutes long.

Mindy H.: Wow.

James Ian: And I wasn't stopping because I'm the drummer and I can't stop.

Mindy H.: Yeah.

James Ian: I could do that. I definitely can't do that now.

Mindy H.: Yeah.

James Ian: I can definitely play songs and take breaks and stuff, but just the stamina is not there. From a guitar's perspective, same thing. I will have to take breaks and stuff. I can't play guitar continuously as long.

Mindy H.: Yeah.

James Ian: I used to play guitar up until, let's say 2018, I was doing three hour guitar shows.

Mindy H.: Wow.

James Ian: Taking a few breaks in between for five minutes here and there, but I could do it.

Mindy H.: Mm-hmm (affirmative).

James Ian: If I'm practiced and rehearsed and in that mode, I could still do that, I think, but you just notice it, but you learn how to adjust. I learned how to rest my arm on the guitar to kind of save it or whatever.

Mindy H.: Mm-hmm (affirmative).

James Ian: I would say those are the instrumental side of things. From a vocal side, airway and stuff, my respiratory is actually... I'm at pretty much 100% for that.

Mindy H.: Awesome.

James Ian: Not from there, but I do get, it's a muscle, I get neck spasms and-

Mindy H.: Okay.

James Ian: My tongue and stuff, that'll spasm up. It doesn't all the time, but it does. I have to account for that if I'm singing and if it does start to happen, I have to kind of adjust and deliver a note-

Mindy H.: Yeah.

James Ian: Where I'm trying to almost mask my tongue. Like I said, it doesn't happen live a ton, but it's a consideration that's there. That would be the main thing for singing for me. It's not really breath, it's the muscle side of it, because SMA affects our muscles.

Mindy H.: Gotcha.

James Ian: Just kind of accounting for that.

Mindy H.: Yeah. But honestly, I think again, you bring up such a good point because we do kind of figure out ways to adjust for or adapt the things that come up. And yeah, I have no doubt that you've come up with methods and things that work for you.

James Ian: Yeah.

Mindy H.: And the other thing I'll say is I did do so much singing in my younger years that I think that it was actually incredibly good exercise for my respiratory function. And so I bet so much of what you do and playing the instruments and everything probably keeps you quite healthy.

James Ian: For sure. Yeah. I definitely think so.

Mindy H.: Mm-hmm (affirmative).

James Ian: And it's like you said too, it's just with the adjustments, it's like, I've made it to a point where no one would know if I even had a muscle spasm or something happen, you know what I mean?

Mindy H.: Mm-hmm (affirmative).

James Ian: You learn to know your body and what you need to do to execute this [inaudible].

Mindy H.: Right.

James Ian: I haven't even really had that issue arise, but it's something I'm aware of, and I'm like, oh, but you just do it in a way that you know how to get the job done.

Mindy H.: Absolutely.

James Ian: As people with SMA or other disabilities, we're really crafty at, because this world was not designed for us.

Mindy H.: Yep.

James Ian: We know how to get what we need to do done and live our lives operating within these parameters that are, they're not fair and the equity is not there, but we know how to do what we got to do because we want to live our lives and stuff.

Mindy H.: Absolutely. Yeah. And I think personally, I think all of us kind of go through our days kind of redesigning the world on a daily basis-

James Ian: 100%

Mindy H.: With the things that we have to accomplish. And so that's a really good segue because I wanted to ask you, we hear a lot about needing more positive representation of individuals with disabilities in the media. And like I said earlier, you're a strong advocate of that. Do you feel we're making progress in Hollywood in terms of inclusion of individuals with disabilities in movies and TVs and commercials?

James Ian: I do, Mindy. I do think we're making little strides here. I think the conversation I'm hearing, that conversation just about what you said, we need more representation, I see that more often. I still think the actual effects of if you look at it from a numbers of how many roles are cast and what percentage represents, we're still not there yet, but I do see people with disabilities landing roles and whatever they might be.

Mindy H.: Mm-hmm (affirmative).

James Ian: I think we're starting to get there. It just could be so much more, but that's how it is from any social justice kind of movement, right?

Mindy H.: Yeah.

James Ian: The needle gets moved. It's not a lot, the needles moved in such small increments-

Mindy H.: Yeah.

James Ian: But it's moved. It takes such a great amount of effort and force to make those small things, but over time where it might not be in our lifetime, but hopefully historically when you look back, you see the progression in where it will get where we want to be eventually, it's such a long time.

Mindy H.: Yeah.

James Ian: I'm really hopeful because I do see small little changes. I want the floodgates to open and just be like, oh, disability, disability, disability. It's all over...

Mindy H.: Absolutely.

James Ian: We're just not there.

Mindy H.: Yeah, for sure. I mean, you're in the thick of it.

James Ian: Yeah.

Mindy H.: This is what you do every single day and you're out there doing the work and doing the acting and the singing and all of that. What can the rest of us do to try to help encourage more of that in the entertainment industry?

James Ian: Yeah. I think from that Mindy, I think also too, the representation needs to be on both sides of the camera.

Mindy H.: Mm-hmm (affirmative).

James Ian: We need people who are writers and directors and producers with disabilities. Also we need that representation to be there too because then that'll pull everyone, I think. That'll just get disability from... It'll be behind the scenes production side of things or the entertainment, the visibility side of things.

Mindy H.: Yeah.

James Ian: I think in the entertainment industry that, and I think just in the world, we need people with disabilities in leadership roles to drive the change everywhere and then we'll start to see disability in corporate boardrooms or peoples who are CEOs of companies or whatever it might be. All of that needs to be there and I think that's what the support is too.

James Ian: And just also trust us to do the work because we talked about it earlier, we're really creative people because-

Mindy H.: Yeah.

James Ian: We had just to survive and so, that creativity is not siphoned off to disability life. That creativity runs throughout every aspect of our lives in our work lives and all that stuff. It's going to be there in all the things that we're doing. And so that's just going to make the world better. I think that's how we support is put people in decision making roles that have disabilities and then also too, if you see that it's not there, then do something to make it there.

Mindy H.: Yeah.

James Ian: [Inaudible] in the room or whatever.

Mindy H.: Yeah, that's such a good answer. What are you working on right now?

James Ian: Right now, I mean, I am in a play that the... I'm in a play that's actually about disability and there are cast members with disabilities. The play runs from the 22nd through the 24th of June. I'm just in rehearsals for that, that's happening.

Mindy H.: And where can people see that?



James Ian: It's in California, there's a museum called the Valley View Relics Museum, that's the space for it. The play is called Schlitzie: Alive and Inside the Decaying Sideshow.

Mindy H.: Mm-hmm (affirmative).

James Ian: And it's about a side show performer who had a disability in the early 1900s, and Schlitzie actually became pretty famous. They were in a movie called Freak, I think, which is a well known, I think, movie. I can't remember the... I think it was in the 50s. And they got a lot of prominence through that movie, but the play kind of deals with the exploitation of sideshow performers, but also during that time, disability was not... People were hidden and stuff. And so there was also people disabilities found community in that space as well. It just show shows both sides of that.

Mindy H.: Uh-huh (affirmative).

James Ian: That's happening. Really excited to be a part of that.

Mindy H.: Very cool.

James Ian: And I have a poetry published in a book at the end of the year, that's a disability of hierarchies book. I think that's coming out of University of Washington. I'm excited about that. I'm auditioning a bunch. Starting, just book more stuff. I just did a print... We talked about representation. I just did a print job back in April. I'm not sure when we'll see the final product for that, but what was cool about that was, and it kind of hit me because I was thinking about it after the fact, but I have a cane in the ad, but I also have a romantic partner in the ad.

James Ian: I'm holding hands and holding arms with someone. And I thought that was really cool because I just realized, even though we're starting to see more disability representation, we don't see the romantic side of things.

Mindy H.: Yeah.

James Ian: We're not painted as romantically or sexually desirable.

Mindy H.: Mm-hmm (affirmative).

James Ian: And I thought this project was cool because when I was on set shooting, they were just like, Hey, do you mind holding hands with this person? And I was [inaudible].

Mindy H.: Yeah.

James Ian: The person was like, do you mind if I hold your head? Just, no, I think this is actually really cool because we don't see disability portrayed as a romantic thing, that we have romantic lives. And I thought that was really cool. Excited for that to be shown.

Mindy H.: Nice.

James Ian: And then I'm going to the Cure SMA conference this week. I'm performing Spaces at, there's a lunch there on Friday.

Mindy H.: Mm-hmm (affirmative).

James Ian: Excited about that. And then there's some projects down the road that are coming up that a lot of times I can't speak about it.

Mindy H.: Yeah. No-

James Ian: Not until afterwards, but some really cool, exciting things about that. And I'm auditioning a lot more, which I'm really excited about and just a lot of pending stuff. And I just did the Special Olympics closing ceremony on site.

Mindy H.: That's right.

James Ian: I performance Spaces.

Mindy H.: Wow.

James Ian: Just really cool. I have performances coming up for music, acting, print stuff, whatever it might be. I just think this one's funny, but I was supposed to walk in the... There was a Tommy Hilfiger adaptive fashion show about a month ago.

Mindy H.: Uh-huh (affirmative).

James Ian: I was supposed to walk into that as a part of... There's an event called the race to erase MS.

Mindy H.: Uh-huh (affirmative).

James Ian: And a lot of celebrities and stuff were there. I was supposed to walk in there when I got to the event, I tested positive for COVID, but it was-

Mindy H.: No.

James Ian: A false positive. I have all the vaccinated, boosted. And I had tested negative a bunch of times afterwards and before. And that was a bummer, but [inaudible].

Mindy H.: Oh, so disappointing.

James Ian: Yes. I miss it for no reason, but I am at least starting to do cool jobs and stuff, and I'm really excited about that and just what's to come. That's where I'm at. I've been working on a script for a long time-

Mindy H.: Oh, wow.

James Ian: [Inaudible]. It's about halfway finished. I do want to put that out there and shop it around once it's done, but I'm contending with all the other things, plus a day job and-

Mindy H.: Right.

James Ian: This stuff happens so short notice a lot of times in the space. That's cool. It looks like also too, the last thing I'll add is I think I might be performing at a really cool... There's an indie, they're a record label, but they have an awards showcase that supposed to be... They asked me about singing at that in New York in September. Looks like I'll be doing that. It's a lot of cool stuff and-

Mindy H.: Yeah.

James Ian: List of events and things I'm doing keeps growing, but...

Mindy H.: You're bored is what you're telling me.

James Ian: Nah. Yeah. I'm getting so much sleep and well rested.

Mindy H.: Oh my gosh. That is so awesome. And what's even better is I also spoke to Leah Zelaya, she's a young actress in the movie Marry Me with JLo and... I mean the two of you are having such huge success and you're such nice people. I love seeing good things happen to good people. I'm really excited for you.

James Ian: Thank you. I'm just happy to be able to audition and just be considered for this stuff. And then when you do get the job, even more of a very cool thing, but it's just an honor to be a disabled person in this time and really showcase what we do that. And it's not just here's our human stuff that we're doing, but we're disabled and we're hopefully bringing light to that. And hopefully these things help to bring other people into whatever they want to do, even if it's not acting or entertainment.

Mindy H.: Mm-hmm (affirmative).

James Ian: If they want to run a company or be a director of operations somewhere, I hope it hopefully creates avenues for them to just do that as a person with a disability.

Mindy H.: I love that. I absolutely love that. I've got two more quick questions for you. I know you're getting ready to travel. And so I do want to ask you, what goals do you have for yourself in the future?

James Ian: Yeah. Honestly, Mindy, this is what I really, really loved. This entertainment stuff is just, like I said, this is what I love to do, it's my heart, it's my driving kind of thing. I really want to be able to make a really solid career out of this. I want to be in more films, I want to have lead roles in films. I would love to be in a lead role on a TV show or have a recurring. I want to do more print stuff. I'm a really big fashion fan. And-

Mindy H.: Yeah,

James Ian: I love that so I want to do more print and runway stuff. And I want to write, I want to have my own TV show and long term, I mean, I went to business school for college so I want to eventually run my own company, run my own production studio or operate.

Mindy H.: Wow.

James Ian: I want to have my own clothing line one day. All that stuff, I want to do that. That's the long term goal, but I'm really having fun. I feel to do that, I need this experience as well. That's the long term and I really want to have... Whatever I do, I want it to be a space where I can hire people who are underrepresented, every underrepresented community, you know what I mean? People of color, people with disabilities, people from the LGBT community-

Mindy H.: Yeah.

James Ian: And be all that good stuff.

Mindy H.: Mm-hmm (affirmative).

James Ian: I'm sorry if I'm forgetting any...

Mindy H.: I know, the whole entire world.

James Ian: Yeah. I want those perspectives in everything and I want those folks to have an opportunity. I just really want to hopefully make it so that other people can also... They can live their dreams too. That's what I want to do, Mindy.

Mindy H.: I love it.

James Ian: Like that. And I love to write. I want to write a book too at some point as well.

Mindy H.: Do it. Absolutely. Such good stuff. For other kids out there who might be listening and have ambitions to act or sing or do fashion or write, what kind of advice would you give to them?

James Ian: I would say really be dedicated to just being better at it. You're always learning, I don't think you're ever going to be at the point where you're the best ever. From that angle, you should always be working to try to get to the point of being the best ever, although I think that's probably unattainable.

Mindy H.: Yeah.

James Ian: And also too, just from talking to older people who have been in the space of doing this work and have disabilities, I know from their experience, they always say people are always looking for a reason to cut you or not give you the job. And especially if you have a disability because there are those misconceptions or prejudices of being like, oh, you're disabled, you're not going to be good. You're not going to be able to act, you're not able to do this role justice. Don't give them, even though it's wrong and false, I still say you want to be the best you can to train really hard, get a vocal teacher, get guitar lessons, drum lessons, whatever it might be, take acting lessons, and just align yourself with mentors who are doing it and who have done it.

James Ian: I think with art, it's kind of so amorphous or ambiguous. It can be so many things and it covers a lot of ground and so many areas. I think you just want to be as well versed in those areas as you can and the training and just doing that gives you that experience. With music and live performances, I've seen so many situations happen that you could never control or even think of, and you have to roll with it and be like, oh, I got to adjust and make sure the show goes smoothly with this variable and I would've never factored in. Just that stuff happens and just [inaudible]-

Mindy H.: Yeah.

James Ian: But that's training for me.

Mindy H.: Yeah.

James Ian: Also too, do as many gigs as you can. You might think they're small gigs that are not worth your time. Trust me, they are worth your time. I've learned so much and gotten other cool things from those shows where I was playing to a crowd of one person.

Mindy H.: Yeah.

James Ian: Do everything starting up, take every opportunity that you can because that's the best practice.

Mindy H.: I would totally agree with that. When I started doing public speaking, I had someone very early on who said, speak everywhere you can. Do it for free, do it for five minutes, do it for an hour, to this group, to that group. And it's so true. It's such good practice, and that's what it's all about. I had another person who asked me when I was starting to do music, she was like, so what's one thing that you do every single day to practice your craft or whatever? And I was like, ooh, I'm supposed to do something every day? And it's true. I mean, practice, practice, practice, train, train, train. Yeah. All very good advice.

James Ian: Yes. I sing every day and I do something acting related every day. And I've heard several times from people in music and acting, they're like, a lot of times, success for people looks like it's overnight, but that's very, very rare.

Mindy H.: Yeah.

James Ian: It may happen for one in whatever cases, but typically, people have been doing it for a long, long time, decades even before we see them and know their names and stuff.

Mindy H.: Right.

James Ian: It's like, all those gigs that you're talking about, Mindy, of speaking for free or doing whatever, those folks were doing that stuff for a very long time. And it all built up to when we see them in what we would call success.

Mindy H.: Absolutely.

James Ian: [Inaudible].

Mindy H.: Definitely. Okay. Is there anything I have not asked you that I should have asked you?

James Ian: No, Mindy, you've covered... I think the questions were great and very thorough and I really appreciate them. I think you've covered all the bases for me.

Mindy H.: Awesome. Well, again, it's been such a joy talking to you and your excitement and your enthusiasm comes through. Just listening to you and I'm so excited for you and everything that's ahead. And I hope that you'll remember us and come back and yeah, just all the success in the world. Thank you for listening. For more information about the guests you heard from today, go check them out at [mda.org/podcast](http://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](http://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.