

Quest

PODCAST



Stay Informed. Join the Conversation.

Episode 11: Siblings Tell All **January 10, 2022**

(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 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 and thank you to our sponsor, Cytokinetics. Cytokinetics is dedicated to supporting the MDA community and to advancing potential medicines for families impacted by neuromuscular disease.

Mindy Henderson: We've got a great conversation for you today, all about siblings. Now, let's get started. Having a sibling can be amazing. Siblings can be built in playmates and best friends, your partner in crime and a constant in an individual's life. Siblings represent deep roots and home for the entire life journey they embark on together. Sibling relationships are not without complications. Today, we're talking to sibling pairs where one of the siblings has a neuromuscular condition and the other does not. We'll explore the dynamics and speak with the siblings, in addition to our resident expert from the Sibling Support Project about considerations and strategies for navigating this relationship. I am so excited to have all of you with me today. How about we do a quick round of introductions? I was saying earlier, before we got started, I've never had this big a panel on one of my podcast before. So I'm really excited, let's start with Abby and Ian, if you all want to introduce yourselves,

Abby Yenser: Hey, I'm Abby Yenser. I am a physical therapist actually at the Muscular Dystrophy Association Clinic at Washington University in St. Louis.

Ian Yenser: I'm her brother, Ian Yenser and I have Becker's muscular dystrophy.

Mindy Henderson: Fantastic. Chris and Danny.

Chris Carol: My name is Chris Carol. I'm from East Norriton, Pennsylvania. I am a sales rep and I am diagnosed with limb-girdle muscular dystrophy type 2D.

Danny: Hello, everyone. I'm Chris's brother, Danny, his older brother by five years and I reside in Springfield, Pennsylvania.

Mindy Henderson: Perfect, and now, let's wrap up our introductions with Emily. Emily, would you tell us a little bit about yourself and about your organization and the services it provides?

Emily Hall: Yes. Thank you, Mindy, and it's so nice to be here with you, Christopher, Danny, Abby and Ian. My name is Emily Hall and I'm the director of the Sibling Support Project. We are an organization located just outside of Seattle, Washington, and we are dedicated to supporting brothers and sisters of people with special developmental health and mental health concerns. We do that work through books and publication, through online support communities for brothers and sisters and through workshops for children which are called Sibshops, that's probably what we're best known for, I see some smiles, some recognition of Sibshops, which is really nice. It's really wonderful to be here today because I think having these conversations, talking with siblings both with and without different health concerns and disabilities is so, so important, particularly to consider both perspectives of that really unique and wonderful relationship.

Mindy Henderson: You're absolutely right. There are definitely, two sides of the coin and each have their own unique perspectives and lenses that they're looking through the relationship with. So, so excited to have all of you here. I love hearing about sibling relationships. I grew up with spinal muscular atrophy and I have a sister who's unaffected by any neuromuscular condition. So, this is a topic near and dear to my heart as well, and my sister and I grew up very, very close. So Chris and Danny, let's start with you guys. Would you tell us a little bit about your relationship, maybe describe your relationship and what you each like best about each other.

Danny: One of the things that I've always thought was great about Christopher is his personality. I always noticed how easy it was for him to talk to people, even like friends of mine, like we're five years older and it'll be like, "Oh, it's saw Chris the other day, man. What a great dude," and stuff like that and that's always been in the back of my head, like with the muscular dystrophy, his personality was never affected. He was always the cool kid, everybody that I talked to, "Oh, Chris is such a cool kid," and growing up with our family, we have five sisters and an older brother who also has a muscular dystrophy. So with Chris, he was the second from the youngest out of eight. So he was just my little brother. So I always felt like, I was his protector, so to say. Would you agree with that, Chris?

Chris Carol: Absolutely, and I mean, in that dynamic growing up as one of the two of the eight that had muscular dystrophy, Danny was always there to make it normal

for me. I remember being diagnosed originally with Becker muscular dystrophy when I was 13 or so, officially, but I noticed it and my parents noticed it when I was in probably about fifth or sixth grade, which they started seeing me, have the same movements as my oldest brother, Richie. Eventually I got diagnosed with limb-girdle doing like genetic testing down the line. It wasn't until I was like 28 where I got an official diagnosis, but once I started to show symptoms, I noticed ... not that we didn't do it before, but I noticed Danny would try and make it as normal as possible with me. Meaning like, let's go throw the football around.

Chris Carol: We had a basketball court in our backyard and anytime I was out there playing, he made sure to come out and just shoot around with me, like different stuff like that, that obviously like I had this physical disability, but like, he was always there to make sure that I didn't let it kind of hold me back in any way when it came to, I don't want to say normal, but normal, like acting as a normal 13, 14 year old kid, and it was just always good because I think Danny took ... like he said, took me under his wing to try and protect me, to try and get me out of it, of that shell.

Mindy Henderson: That's awesome. Abby and Ian, what about you guys?

Abby Yenzer: So we've got a little different story and background. So Becker is an X-linked diagnosis, so my uncle, our uncle, my mom's brother had Becker. So we kind of grew up very familiar with this world and I guess what being disabled or having limitations looked like, but I was not aware that Ian had this diagnosis very young, so we just ... we're kids, he played sports and-

Ian Yenzer: Yeah, for the most part you couldn't really notice unless I explained it, that that was going on. Of course, I noticed in grade school that I was slower or that I would walk a little different, run different, but I always knew having my uncle, we were around him all the time. We were helping him with little stuff throughout the day, and I think it was really normal.

Abby Yenzer: Yeah. That was a big part of-

Ian Yenzer: I mean, my cousin as well, who's a couple years younger than me has Beckers as well. So it has been part of our family going to the different events with MDA and all that. It's pretty normal.

Abby Yenzer: Yeah. I don't know, like growing up, just ... I think it was maybe when you were in fifth grade that I started to ... like I was more aware of the differences and like my parents talked to us a little bit more about it, but as kids, we were just kids and I feel like we got in a lot of trouble. We were not like kind siblings to each other. We were aggressive and honorary and stubborn and like we were ... I think we've gotten closer off and on throughout the years, definitely closer now as adults than we were as kids, but we had a lot of fun times, so a lot of silly times. Yeah, it was just little different start to that relationship.

Mindy Henderson: Yeah. Well, I can tell, and getting to know you the last couple of weeks, working toward the podcast, I can tell that you guys have a very nice relationship. It's

been fun to get to know you. So let me ask you, Abby and Danny, how did it feel to have a sibling with a disability? What was that like growing up? Did you notice that they got treated differently by other people or what was it like for you?

Abby Yenzler: Growing up, early on, it wasn't different to me, just because we had so much experience with it in the family, I just was like, this is part of life and it wasn't until maybe high school, sometimes in grade school where my friends are ... people would just ask, from my perspective, it wasn't ever rude or anything like that, but it would just be like, "Hey, is your brother okay? Did he hurt himself?" I'm like, "Yeah, he's fine. He seems fine to me." Actually, one of the ... a memory from high school was, someone had ... a common feature in Becker muscular dystrophy is large calves, and I was walking down the hallway in high school and someone asked me like, "Do your brother play soccer?" And to me that was ... I don't want to say ridiculous, but I'm like, "No. Sorry. Yes, no. He has a disease." I had to like recollect myself because it really was just our life. I didn't think of it as anything different, and he was always very ... we were both very independent.

Mindy Henderson: Awesome. What about you for you guys, Danny?

Danny: For me, it was slightly different because I had Richie who I think is close to five years older than me and Christopher, who's five years younger than me. So growing as a young kid, I'm looking at my brother Richie and I don't think anything of it, as a young kid. Then, when you come to the realization that something is wrong with him, and then you're old enough to get it explained to you that what he has is muscular dystrophy and this is ... he's walking different and I'm starting to get into sports, and looking up at Richie who's five years older and like, all right, well, he didn't play. He was on the football team, but really he didn't play that much and then, I'm thinking to myself, am I going to be that same one? Am I not going to be able to play?

Danny: Then, in the realization, I didn't have it and everything is fine with me, so I kind of took a different approach with Christopher to make him not feel, how I was thinking Richie might have felt. So even with that, I guess personal standpoint from it, I think I put a lot of pressure on myself to like push me my body to the limit, so to say, like in sports, I never felt like I was satisfied with what I could do, knowing that Richie had what he has, Chris has what he has and I'm like, kind of in the middle, so to say, almost like, why don't I have it, if those two have it.

Mindy Henderson: That's interesting.

Danny: Yeah.

Mindy Henderson: I kind of want to come back to that in just a minute, but let me circle back to Chris and Ian, having a sibling who's unaffected, for me, there were feelings, there was a little bit of jealousy that I couldn't do some of what my sister could do and things like that. What was it like for you, was Danny just your brother, Chris or were there emotions and feelings around the disparity?

Chris Carol: No, not ... I mean, were there emotions? Yes, but not towards just Danny. I had five sisters and one brother that didn't have it. Now, when it ... once I got older and I started really getting into like the MDA and everything like that, it made a lot more sense with limb-girdle muscular dystrophy as to why me and Richie had it, like it's recessive and it was 25% chance and it was, 25% of us got it. So that made a lot more sense down the line, but when I was a child, I thought, why did it skip six people and then come to me? It wasn't like directed towards Danny. It wasn't directed towards Teri, any of my other sisters. It was just like, why was it skipped so many times then me, then I had a little sister as well who doesn't have it. It wasn't like any ... I don't want to say it was jealousy because the fact that I always looked at it as if I didn't have muscular dystrophy, I might be better at basketball than Danny is.

Chris Carol: Well, four of my five sisters were all like college track ... or like they all ran cross country or ran track and I got into them their sports. I was a ball boy for Danny's football team, when my sisters had track me. I always made sure ... like I enjoyed going to that kind of stuff. So that's why like, looking back on it, there was never any like jealousy, because I think if there was jealousy towards it, I would resent them for being so good at certain things, the way I looked at, I mean, and if I didn't have muscular dystrophy, I would be probably right there with them doing all this stuff but it was just kind of like easier said than done sometimes, but I think it was like the hand I was dealt and just tried to make the most of it.

Mindy Henderson: That's really nice. That's really ... Ian, what about you?

Ian Yenzler: So I definitely think I felt a little bit of probably jealousy, not that I wanted what she's able to do, but I felt like, just walking around in high school just in general, in a fatigue and like trying to stay upright and trying to walk as normal as possible, took so much cerebral focus, that I wasn't getting out the other parts, that was taken up so much of my energy. And then, seeing my sister, she has always been pretty successful at different extra curricular activities, but swimming was a big one for her, he was pretty good at it, and I know she put a lot of effort into that but what Christopher said is like, I'm putting a lot of effort into it, and I believe if I didn't have the disease, man, I'd be able to give her a run for her money.

Mindy Henderson: Right.

Ian Yenzler: In some of that, when I was talking about jealousy, is seeing that, is kind of wanting that recognition for myself, like something that shows for the work that I did and like feeling that she or a lot of people didn't really know that it took that sort of internal effort.

Mindy Henderson: That makes sense. So we've kind of touched on a few different themes here and Emily, I want to bring you into the conversation, we've heard a little bit about some jealousy, about some guilt. Could you talk to us a little bit from your perspective and the siblings that you've worked with over the years, what do you see as being sort of the main more dominant issues that you tend to see between this kind of relationship?

Emily Hall: Yeah. Well, first of all, it's so insightful to hear perspectives of the experience of growing up with a neuromuscular condition in the family, from both the person who has it and the sibling of the person who has it. I've heard a lot of themes that have come up that are really pretty common in terms of the sibling experience. So we work a lot with siblings of people, who have physical conditions, maybe cognitive conditions. One of the things that we often say is that the sibling experience really parallels the parent experience. There's research, a lot of research that really documents that and there's less research that confirms what we're hearing today, which is that siblings both with and without the condition also have similar experiences. So first I just want to talk about ... Abby, you talked about this and Danny, you've talked about this as well, kind of your baseline.

Emily Hall: I agree, whoever said, I don't want to use the word normal. Chris, I think it was you. Someone once told me, normal is a setting on a washing machine. That's pretty much it, which I really liked, because I think it's true, like what is normal, but our brothers and sisters ... and I am a sibling, as well. I didn't mention that in my intro. I wish my brother was here right now because we're all together, it's making me miss him. Anyway, all we know in life is what we know our experiences and our families. So, like our brothers and sisters are our normal. So, oftentimes siblings recognize that there's something different, not through their own observations, but by how other people treat their brothers and sisters or the comments and questions maybe that come their way. Abby, it sounds like you got a fair number of those questions, but not as unkindly as can be sometimes by children, right?

Emily Hall: Kids can be pretty mean. Also, this idea of kind of putting the pieces together, Danny, you sort of talking about, kind of observing, well, this is what's going on with my older brother and this is what he's able to do and maybe not able to do as much. Now, I have this younger brother and he has this similar condition and will I have this? Sort of putting the pieces together, how is going to impact me, because a lot of times, families aren't having those conversations, parents are often hesitant to share that information with siblings and also the kid who's affected, right? I've heard many people say like, well, we didn't really talk about it. Even though, I knew there was something going on with me, but we didn't talk about it as a family and I think parents do that for the best and most loving reasons.

Emily Hall: They don't want to worry or burden their children. It also can create some questions, and this feeling that this is a taboo topic that we can't talk about, and I'm going to have to kind of piece this together myself. Also, Danny talking about the fact that you put a lot of pressure on yourself to really push yourself in sports, because you were not affected by this condition, because your body would allow you to, because you had this gift of physical ability that you felt like you had to make the most of it and that's really common amongst siblings, that because I'm not affected, I'm going to push myself and be kind of the perfect kid, the overachiever, the kiddo who's going to sort of balance out the scales in the family and achieve enough for everyone, which is great because you have a lot of siblings or these like overachievers and it has a cost because sometimes that pressure can be a lot and it's hard to release yourself of that pressure.

Emily Hall: So I think all of those are really, really common experiences, and I really think it's so important that we talk about jealousy, and from the perspective of both siblings, this is something that we do talk about with siblings, a lot sort of being jealous of the time and attention that the person with the illness or the condition receives from parents, because the truth is a lot of times there are needs that need to be taken care of, whether it's through hospital visits or therapies or doctor visit. A lot of siblings can kind of feel left out of that, and I also think it's so interesting to hear from the other perspective. Well, I was also jealous because you could do all these things that I couldn't do. By the way, I love the healthy sibling competition with these pairs here.

Emily Hall: By the way, if I didn't have this condition, I'm pretty sure I'd be just as good if not, better than you, right? So I love that kind of like ... that healthy sibling rivalry and I think it's so important to recognize that jealousy really is kind of a two way street, like the grass is always greener.

Mindy Henderson: Yeah. It's such good points that you make and I'm thinking back to my own childhood and I do want to talk for just a second about parents because we may very well have a lot of parents listening, and I think that one of the things that my parents did really well was to encourage me to find things, were kind of in my wheelhouse, my sister was a dancer and did a few other things along the way, and I really enjoyed music, and singing and all of that. So that was something that I got really involved in because my parents really encouraged me to find those things that could fulfill and make me happy while my sister was off doing her thing. I want to throw this other question out there because it also ties in, Emily to what you were saying, but I am curious to know, and whoever wants to catch this question, feel free.

Mindy Henderson: I'm curious to know how your parents did explain the condition to all of you, whether you were the affected person or an unaffected sibling. Was it something that your family has talked about?

Chris Carol: For myself, I, watching my oldest brother, and it was kind of what we just talked about, but watching him, I started to notice I was doing some of the same stuff. I noticed when I was running, like my shoulders were going up in the air, like I was running a little differently. I was going up and down steps a little differently. Like Ian said earlier, I noticed I had large calf muscles and at the time I'm like, "That's not a bad side effect." It was more so ... I think at the time, it was unspoken. I know, I think my parents knew, but it wasn't until probably a few years later that I remember we were sitting there, I was in my kitchen and I remember going to the doctor and getting blood work and then a week or so later, my mom was like, "That blood work came back, you have a high CPK level and we think you probably have the same thing," that my brother Richie has.

Chris Carol: I remember thinking, it was a relief where I was just like, "Okay, this is it," but I was also like, it must have been hard for my mom. I never thought of it that way until later on. Maybe that's why they didn't say right away, like God, I don't know, but it was more like ... I was just like, okay, I knew and I was kind of like, just trying to be strong about it and I was like, "All right, now let's ..." because still, I mean, there's no cure now, but at the time, I just said, "There's nothing we

can do," kind of make the most of this. So that's basically how I found, it was just a quick conversation in the kitchen, and that was kind of the end of it and then I started going to children's hospitals.

Danny: If I can chime in real quick, there was never a time, like when we were younger before Chris was even around, when Richie ... we started noticing Richie had it. It wasn't like my parents sat us all down at the table and gave us a breakdown of what Richie had. I think we all started even at a young age noticing something was different. I think they pretty much just explained that it's muscle dystrophy. We think it's this. They're telling us that know it's this, but never ever was it ever like treat Richie differently where then Chris comes along or treat Chris differently, and I think that's pretty good for my parents from their standpoint, because I don't think Chris, you can vouch for this too. It was never a special treatment for either one of them and I think that's in a good way, so to say.

Danny: We never treated Richie or Chris differently. We obviously knew, we obviously knew you couldn't just run by them and throw a shoulder into them or anything like that. They were never treated as the number one, like, "Oh, pizza night, Richie and Chris get the pizza first. You guys all wait." It was never like that, so I think that-

Chris Carol: I would 100% agree with that, and the only other thing like speaking about when my old oldest brother was diagnosed, he went through all that. He went through the muscle biopsies, he went through all the tests that they put him through, down at the University of Penn. I didn't have to go through all that. Once, I started showing symptoms, it was kind of like, "Okay, yeah, Chris must have it as well." Like I said before, I mean, genetic testing, wasn't a thing back then. It wasn't until, I guess 15, 20 years later that I basically spit into a tube and I got diagnosed two weeks later. That wasn't available back then, so it was kind of just like ... it looks like Becker, it might as well be Becker, and I think what Danny was saying, like I never thought that like home was kind of like a safe place for me growing up.

Chris Carol: Meaning that like, I didn't have to ... I would lie to people as to what was wrong with me, unless they were like my closest friends, I would say like, "Oh, I twisted my ..." like I wouldn't make up stuff about why I was walking slow or why I couldn't do certain things in gym class. Like Ian was saying, the cerebral part of it, trying to walk as normal, like walking with a strut, just to kind of hide the fact that something was wrong with me to keep like ... that's a lot of work and it was at home just being treated normal and being able to just act normal. It was just like ... I mean, I got yelled at as much everybody else. Even like Danny said, like I played basketball, I didn't played much but my parents were at the games, just like Danny.

Chris Carol: They were at his games and he was starting at like ... so it wasn't ever anything like that. So it was always kind of equal across the board, all eight kids.

Mindy Henderson: Awesome. Awesome. Abby, I want to ask you, my sister often pitched in when we were kids and helped me and would do things for me even, yeah, after she and I had both moved out of our parents' house, she would come over

sometimes and help me with different bits of care, and that sort of thing. Was much of that expected of you as you were growing up and if so, how did it feel to be both a kid and a caretaker?

Abby Yenzer: Honestly, as a kid, I had a lot of responsibilities, but not with Ian, with my uncle. So, I just always assumed that that was going to be part of my life. I will say that there are times that I ... weaker times in my mental health where I resented that, I'm like that extra effort of doing something that no one else sees, I wanted to just live life and as we got older, I was like "But this is my family," and then I'm like, no, we thought about moving away. My husband and I were like, "Let's go to Scotland. That seems like fun," and we were both just like, "No, we like our families too much." I'm like, "Yeah, I want to be there and I want to help my family because ..." I mean, that's what we are, we're family. Honestly, I think we've had more fun together working on like physical therapy and stretching than we did playing as kids.

Abby Yenzer: There are things that I've done working with Ian that I could not do with any other client, to make sure that he's as comfortable as possible, because I know that this disease for him is hard. It's painful, it's uncomfortable and having that knowledge, like that's part of why I do what I do, because I want to be able to be there.

Mindy Henderson: That's really great. Emily, I want to ask you a couple of questions actually, because a few of the things that Abby just said, kind of jogged this in my own mind. I'm curious about playing and I'm curious, when you've got two or more kids with different abilities, how do you work out and encourage siblings and help parents to understand appropriate play and how to get kids working together and playing together well?

Emily Hall: That's a great question Mindy and we get this question a lot from parents. I just want my kids to be able to play together. I just want them to find common ground. So I think a lot of it really is sort of identifying those games or activities that kids can enjoy together, and also understanding that the siblings aren't going to be able to necessarily do everything together and everything the same way, which is why I love Mindy your own story, about how your parents encouraged you to find your thing and how for you, that was music and for your sister, it was dance. You each kind of had your separate identities and the things that made you happy. Abby, you kind of said the same thing, like Ian always has had his own friends and like he's done his own thing.

Emily Hall: And you know, Danny is saying, "Yeah, Chris was the cool kid. He had his own thing going on." So I think the more that we can encourage parents to really embrace that idea, that every child is unique and help them find and nurture those things that they love to do and make them happy based on their skills and their abilities and also finding those common grounds. Honestly, I don't think that that's too different in general for any parent, right? Especially if you have kids of maybe different ages, for example. At home, we have a nine year old and a five year old and it's really hard for us sometimes to find activities that they'll both enjoy because developmentally they're different stages. For us, there's a

lot of Uno that goes on in our house because it's a game that we found that they both can play and enjoy.

Emily Hall: So whatever that is, and I think that this points also to something that Chris, you said, that is so important when we talk about how to support siblings with and without disabilities and different conditions. One thing that we hear a lot from siblings in particular who say we did pretty well in this department of not necessarily feeling resentful or jealous of each other. There are a couple of great things that our parents did and one is that they really did set equal expectations for both kids. So, Chris, I love how you say, like I got yelled at just as much as everyone else, right? Home was a safe space where you were just another kid, right? Where your physical condition did not define you and it did not define your relationships with people in the house.

Emily Hall: You were just another kid. So, to have the same expectations of all children to the greatest extent possible, I think is really, really helpful, that's what we've heard for years for both siblings, affected and not affected. Then, the other thing which speaks to the question you just asked Mindy is that if there is something that brings a family together, maybe it's music or sports or maybe it's church or religious community, but if there's something that brings together the family outside of just the diagnosis, like outside of the disability that enables everyone to participate fully and has nothing to do with the neuromuscular condition in this case, that can be really, really helpful to bring a family together.

Mindy Henderson: Absolutely and yeah, I'm getting flooded with memories from when I was a kid and I also loved, Chris your comment about getting yelled at her scolded as much as anybody else. I had to set the table and my sister had to empty the trash, and we all kind of had to pull our own weight and have equal responsibilities and things. So what was helpful to all of you in terms of resources and coping mechanisms as you grew up?

Abby Yenzer: I guess, I saw my parent, or my mom and her brother and their other sister's relationship and really just tried to be better, and that's honestly, one of my favorite things about Ian is he always tries to be better. He tries to be the best version of himself that he can be. We look to each other for support, we have a very small, tight knit family and we've always been involved with the MDA. So really it was just kind of those outlets, but I don't think I really had anything outside of that, but for all of our disagreements and arguments and fighting and bickering, we're a pretty close family, and I think that was the main support that we had.

Mindy Henderson: Well, and I think too, this is a very specific circumstance, but any family that you look at has their own set of circumstances and adversity and all of that, and I personally would say, our family was very close to the muscular dystrophy association and they of course, were a great resource and help to us. Other than that, we all just kind of did the best we could and worked it out. So what you're saying really resonates with me, Abby. Chris and Danny, was there anything for you guys or do you have kind of the same answer?

Danny: From what I remember there was nothing ... like it was normal, Richie is the oldest, so obviously my parents' view on it would be a little different and how they would cope with it. Growing up, once you got to the realization you were at the age where you understood everything, it was normal. Then, when Chris came we realized Chris had it, it was normal to us, we were used to it. Then obviously, when they're going through their changes, like you could see Richie could walk in college, like Chris said with the type of walking, but he was still walking and then gradually, now he's in a wheelchair and obviously, Chris is in a wheelchair now too. So coping with that, I think it was ... I guess we did it in our own ways, so to say, like brothers and sisters, we would probably talk to each other about it, but it was never like, "Now he's in a wheelchair. What do we do now?"

Danny: I think I looked at them and if Richie was upset about it, or Chris was upset about it, maybe that would make me more upset about it, but the way they handled it was like, "All right, now I got to deal with this." What do you think Chris?

Chris Carol: I would even go as far as saying like, I didn't really cope with it. Growing up, I kind of just ignored it. It got to the point where I was like, I'm not going to let muscular dystrophy ruin my life, to ruin my life. I like got that into my brain so much that I just completely would, "I don't have it." That's how I looked at it and that's why I would hide it from people unless like my close knit group of grade school friends, they knew and people knew but nobody knew really the extent of it and all through college, like I went to Penn state, like all through college, I may deal with it. It wasn't until college that I got like a handicap placard. Stuff like that, it's like little small changes like that, that if I had to, I would deal with it, but for the most part, I just ignored it as much as possible.

Chris Carol: If I was in a room of people and I couldn't get out of a chair or I couldn't get off the couch, I would wait for people to leave the room and then I would get up when I was comfortable around people. Stuff like that, that like, was that healthy? Absolutely not, because it put me into some like dark places mentally that I just like ... it just wasn't good for me and it wasn't until ... like Danny said, I'm in a wheelchair now. I was walking up until I was 28. I was hit by a car and I've been in a chair ever since. I wasn't able to get the strength back but that decision was taken out of my hands. Richie had to make a decision to get into a power chair, to get into a manual chair. I didn't have to do that. I got hit by a car, so I was in a wheelchair and then the muscular dystrophy kept me off my feet.

Chris Carol: It wasn't until then that I was like, "Okay, now I have an excuse to be in a wheelchair, like I got hit by ..." so it was another reason not to cope with it because now I could just say to people, "Oh, why are you in a wheelchair? Oh, I got hit by a car." It wasn't until like I met my now wife at the time, my wife, Joyce, she really started pushing me towards getting involved. It kind of just fell on my lap to be an ambassador for the MDA, and that's how I started. Since then, that is how I've been able to cope with everything. Since that's happened, I've been like kind of a completely different person. It's more like embracing it and living with it, rather than hiding from it. That is how I technically coped with

it growing up. Like Danny said, in our house, it was normal. So like, I would deal with it like that on the outside world but once I was in our house like-

Danny: Is that wrong? Is it wrong that we treated it like it was the norm?

Chris Carol: I think it helped me because I would never shy away from asking people for help, like in our house. Outside, I would but when we were home like-

Danny: Yeah, it was never ignored that you guys had muscular dystrophy. It wasn't like that, we were like, "All right, pretend it's not even ... like they're both fine." It was never like that. I think what I'm trying to say, and I think Chris will agree, we treated it like the norm. They were normal to us. I didn't look at him differently. I knew something was wrong. I knew something was wrong with Richie and both Chris, they have two different personalities, both Richie and Christopher. So I could talk with Richie about one thing, Chris about another. It wasn't about muscular dystrophy. With Richie, when I was younger, it was about wrestling, WWF. Now, with Christopher, we would talk about sports constantly. I guess, I knew Chris had feelings that he wasn't showing and maybe that I'm that I'm older. I'm like, "Oh, you should have told me, we could have talked."

Danny: Now, we probably would be able to talk and maybe as youngsters, when he was going through that, say he's at 16, I'm 21, that's not what you sit there and talk about like, "Oh, your emotions, so to say." Would you end up right there Chris or no?

Chris Carol: Yeah, but even growing up like yeah, I would ... I wear it like on my sleeve now, but growing up, I wouldn't want to talk about that to anybody. It's just like the way it was like that. That's just the way I approached it, like yeah, I have muscular dystrophy, but don't worry about it. It was like, if I fell down out in public, my closest friends knew how to pick me up. They knew what they had to do to pick me up. That was ... I looked at that as being, like I was lucky for stuff like that. I was lucky to be able to go home and like be treated normal. I don't know. It was just like a situation where, like I thought I was better off just ignoring it at the time and like getting past it.

Mindy Henderson: It sounds like it was ... for all of us, it was, yeah, our disability was always present, but not primary. Like you're saying, it was our normal and Emily, I think that you may have opened by saying, our families, our first version of normal to us, it's what we grow up knowing and being comfortable with. So Emily, I would love for you just to take a second, talking about these Sibshops and what sorts of activities and approaches you take with kids to help them work through these issues when they're young?

Emily Hall: So Sibshops are workshops primarily for school age, brothers and sisters, of kids with a variety of abilities and disabilities. They really provide a combination of information and peer support in a highly recreational setting. So Sibshops are first and foremost fun. They appeal to kids who like to play. So we really center around play. We also provide opportunities for siblings to talk about what it's like to have a brother or sister who has some kind of disability. I can't emphasize enough how important the peer support component is because all of us who

facilitate at Sibshops, we understand that we're not the experts in the room and it's really, the kids who are the experts of their own experience and the ability to talk each other through those sticky situations, we sometimes find ourselves in that's really best left to kids who are living it every day.

Emily Hall: So Sibshops are ... they might look a little bit different in different locations. There are over 550 Sibshops around the world, and they might meet on different days of the week for different lengths of time, but they always include those components of information, peer support and a lot of fun.

Mindy Henderson: That's fantastic, and Emily, I want to go back to the siblings in just a second, and ask them some fun questions about their relationships, but do you have any sort of final thoughts or resources, or anything that you want to leave our listeners with?

Emily Hall: Well, first of all, I think it's so ... as I said in the beginning, I think it's so helpful and insightful and enlightening even to hear these conversations and I'm curious just to ask, if you all have had these conversations before? Is this the first time you're talking as a sibling pair about the muscular dystrophy? Chris and Danny, is this the first time you've really talked about this in this kind of way with each other?

Danny: I'm just finding it out now that he has muscular dystrophy.

Emily Hall: Well, hopefully that's not the case.

Danny: I'm a little surprised, but no, I don't think ... I think kind of like what I was talking about before, it was never ... Chris, did we ever have like a conversation other than now that ... like you even said, you wear it on your sleeve now, you want to talk about it more now than you did growing up, but I'm sure we've had conversations about muscular dystrophy.

Chris Carol: Yeah, no. Yes, we've talked about it before and we've had conversations about it. I've known how Danny has felt about it before, being the one brother who doesn't have it, never in like a formal setting like this to the MDA world, but yes, we've talked about it.

Emily Hall: Yeah and how about you, Abby and Ian?

Abby Yenser: I don't think the two of us have just sat down and chatted about it before actually it was-

Ian Yenser: I've never done anything like this.

Abby Yenser: So I came down, this is his little apartment in our parents' basement and I came down and I was like, "Okay, here's the questions?" He's just like, "Oh God," like we have never reached these topics before, we tried to keep everything light and fun and happy. So, it's a little different, I think it's good for us honestly, but yeah. I mean, we knew about the disease, we knew about everything that was going on, but we're not a real big feelings family.

Emily Hall: Yeah, and I think that that's probably more common Abby and Ian, your experience, maybe not necessarily sitting down and talking about it and it totally depends on culture and family and how we communicate and what we talk about as the family, but it's clear in both of your cases that you have very close bonds with one another and that sometimes it's even the unspoken things that make those bonds even stronger. At the same time, I think about you, Danny and Chris and both of you kind of realizing during this conversation today, "Oh, maybe it would've helped to talk about it in a different way growing up." So this is a very long way of answering your question Mindy, to say that, I think it's always helpful for families to encourage dialogue about the disability in a really open ended way.

Emily Hall: Here's this thing, here's this situation, here's this reality that all of us are living with and we all have kind of a different perspective on the situation, and what's it like for you? I mean, maybe just like an open-ended question like that, what is it like for you? What is important for me to understand? These might not be the words you use, they might not be the most natural, like let's sit down and talk about it. I do encourage parents to communicate with their children and to encourage communication with their children, especially young children. So that they're ... if there are questions, they have reliable sources for information, and they're not just sort of left to their own devices to figure things out or wonder, is this something that will happen to me too, or to wonder, well, how can I help my sibling? Whether you are the person with the disability or not, right?

Mindy Henderson: That's a really good point. I love that, and I think that one of the things that my parents did, I had a number of surgeries growing up and one or two of them were relatively serious and have long recovery periods, and I think that what I've leaned since those things happened, years later looking back, I think that those were probably scary situations for my sister. I think that my parents did a good job of sort of explaining to her what was going to happen, what it was going to be like when I came home and how I was going to be feeling and that I was going to get better. It was maybe going to take two months, three months, six months, but I was going to feel better and things that she could do to help along the way that made her feel better also.

Mindy Henderson: Sometimes it can feel good to be able to do something to help. So, I think I'd want to go to all of our siblings here and I just want to close it out by asking what you wish the world knew about your sibling.

Ian Yenser: I would say something to do with her career choice, what she made ... her life is something that directly helps me and people like me, and I think that would be something that I'm proud of her. It means a lot to me. The fact that she devoted a lot of her life to these conditions is just-

Mindy Henderson: Special.

Ian Yenser: Yeah. There you go. Special.

Mindy Henderson: Yeah. Abby, what about you?

Abby Yenzer: I think, he mentioned it a little bit earlier too, but just how hard he works at everything that he does, and the fact that even the smallest things are so much harder for him and yet, he still gets up and does them, like going out to eat with the family. If he has to shower before that, that's an entire day's worth of energy, but he still shows up and hangs out with our entire small extended family for get togethers and is there, and is cheerful and literally the star of the show, our entire family loves this kid.

Mindy Henderson: I could see why.

Abby Yenzer: He got a little bit of bravado when he gets out there. He's a fun kid.

Mindy Henderson: That's really nice. Chris, Danny, who wants to go first?

Chris Carol: I'll go. I will say about Danny. I mean, number one, he's an amazing brother. Just growing up, he's like ... if the way he approached muscular dystrophy is that he had to take me kind of under his wing and be my protector, he did an amazing job at it to make me try and feel because as we spoke about before, like parents trying to get kids to find their niche, find ... mine was sports, I love sports and it was something that I really couldn't do and Danny was there to kind of be my partner with that. I would also say he's an amazing father to my two nephews. Being a father now, I have a one year old and a baby on the way, I hope to have as much focus on my kids as he does on his, and it's good to see, like they're two awesome kids and I think that's all because of him.

Danny: One thing the world should know about Christopher is he's a neat freak. Everything's runs to that. I think you ... how many times you run the vacuum a day, like four or five times, three?

Chris Carol: I think I sweep probably twice and run the vacuum twice.

Danny: He's been like that since he was younger.

Chris Carol: Especially working from home now, like I have to clean up after three meals a day rather than one.

Danny: I don't want to be a copycat, but I'm going to pretty much say the same thing about him is he's been a great brother and always will be a great brother. I'm looking at him now and I see that he is a dad of a one year old and one on the way and happily married, so I'm proud of him. I think he does great at work and it seems like the people at work think he's great, which is awesome. Even with all the kids, the new baby is going to be the 23rd grandchild for my parents. So that's 21 kids that he's been an uncle to before his babies have come along and he is always been great with all his nieces and nephews. So he's become a great man, to be honest with you.

Mindy Henderson: That's really nice. Well, I think you're all amazing. Can we just hang out all the time? This has been so much fun. I think that you're all fantastic and I can't thank you enough for ... I know that some of the topics are a little bit uncomfortable to talk about, especially with your sibling present. I really

appreciate all of you being willing to come and talk and share your stories for the sake of others who may be listening and needing some advice, so thank you all.

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.