**S1:** So. Hey, Eve. My name is Monty. I'm a medical student here at Njms. I'm here with a moog and Abby, who are like, some other medical students, and we're all trying to look at scoliosis and, how a lot of patients who are being treated for scoliosis with bracing or feeling, during their treatment. So is it okay if we ask you a couple of questions? Yeah. All right, so first I just want to get to know you a little bit. Yeah. So, like, how old are you? [0:00:31.5]

**S2:** Okay. So, I mean, like, how old was I? [0:00:36.5]

**S1:** I guess these you can answer, I don't know. Okay, answer. Like what? [0:00:41.5]

**S2:** Right now I'm 15, and yeah, when I was bracing, I was it was like between the ages of 11 to 13. [0:00:49.2]

**S1:** Oh, okay. So were you diagnosed earlier? Like, do you want to tell me a little bit about, like, how that happened when you were first diagnosed? [0:00:59.1]

**S2:** Yeah. So I missed the screening in fifth grade when I was like ten. So I was diagnosed a little bit late, like, I think it was. I'm not really sure when when I was 11, but I was almost 12. And so yeah, I was diagnosed pretty late and, and so like maybe it was spring, I'm not super sure, but. Yeah. [0:01:19.3]

**S1:** And like right when you were diagnosed, was there talk about bracing or was there a little bit of like time in between? [0:01:25.8]

**S2:** When I was diagnosed. It? Not there wasn't really much talk about like there was some time in between, like, oh, we got x rays first and like that. [0:01:37.9]

**S1:** Okay, so then when you were told like that, you would maybe have to start bracing and like, this whole journey. Like, how did that make you feel? [0:01:47.1]

**S2:** To be honest, I didn't really think I did that much. Yeah. It didn't it didn't really feel like a big deal because, I think part of the reason why is because, like, it was like Covid back then, so like I wasn't going into school at all, so. [0:02:01.7]

**S1:** Gotcha. Did things like change a little bit once you started like once you went back to school after Covid? [0:02:08.0]

**S2:** Well, yeah, it was a little weird, but like. I mean, I was used to the brace by then, so. [0:02:15.9]

**S1:** Yeah. Did you always, like, wear it during school or like, did you wear it mostly at home? [0:02:22.6]

**S2:** Oh, I wore it basically all the time. I kind of liked wearing it. [0:02:26.2]

**S1:** Yeah. You liked wearing it? Okay. Was it something that, like, you were able to, like, talk openly, like, with your friends about? [0:02:34.6]

**S2:** I didn't really, like, know with my friends. Not really with my, like, with my family, of course, but, like, not really with my friends. [0:02:44.0]

**S1:** Was there any, like, reason why, like, you didn't feel comfortable sharing that with them? Or is it it just, like, not really come up? [0:02:50.9]

**S2:** It was, it was just kind of like a like, I don't know, like, I just like, I don't know, like, it just didn't really come up and I didn't want to, like, bring it up, you know? But, Yeah. No, like, like with my classmates. It was just a little bit awkward, you know? But, I was like, fine with talking about it. [0:03:14.0]

**S1:** Why would you say it was awkward? Like, with your classmates, if you don't mind sharing? [0:03:18.4]

**S2:** You know, it was a little bit of like a pity party, you know, like, if you wear it, it's. Yeah. So I didn't want to, like, I didn't want to seem like I was inviting, like, that kind of thing. [0:03:30.9]

**S1:** Yeah. That's understandable. I wore a, I had, I had scoliosis as well. So I wore a back brace throughout middle school. So I definitely understand, like, how you're feeling. Do you think it was something like, did a lot of your classmates, like, know what scoliosis was? Or like, if they did somehow, like, find out about it? [0:03:49.9]

**S2:** Oh, no. Sometimes, like once or twice, and especially when I was changing for gym, obviously, like, I had to take off my brace and everything and like, once or twice, I like, wore just the brace with, like, an undershirt and nothing on top. So, like, people like, could see my brace, and, and none of them really understood what it was. So like, usually they just like. Most people just didn't mention it. But like if someone did, they just come up to me like, oh, like, are you okay? No, I that was pretty annoying, honestly. But like, yeah, I like nobody made like, a huge deal about it. Okay. [0:04:24.5]

**S1:** Did your back brace ever make you, like, feel insecure in any way. [0:04:29.0]

**S2:** You know? [0:04:30.2]

**S1:** Questionable question. [0:04:31.9]

**S2:** I kind, I thought it kind of looked cool, honestly, like. Yeah, it's like, I don't know, that's why I wore it sometimes without, like, anything on top. When you did wear, like, a shirt over it, it could be pretty ugly, though. It made the shirt, like, all, like, lumpy, but like. Yeah. [0:04:48.5]

**S1:** Okay, so you never, ever, like, felt like you didn't want to wear it in certain settings. [0:04:55.1]

**S2:** Like. I, I mean, I was like 13, like, I wasn't, I wasn't like I was going anywhere where I had to look good. Right. So like, yeah. So I was fine wearing it to school. I usually just, okay. It did make my clothes look kind of bad. So I mean, like, I'm not gonna lie, it did look kind of bad, but, like, just just it plus, like, an undershirt or whatever, it wasn't, like, ugly. It was fine. Yeah. [0:05:22.8]

**S1:** Did you feel like, supported by your family and your friends that did know about it? Like at the time? [0:05:28.7]

**S2:** My family was. Yeah, my family was pretty normal about it. My friends. I didn't like to be pitied, so that wasn't annoying. But like, other than that, everyone was really fine about it. [0:05:41.4]

**S1:** Yeah. And was it ever, like, uncomfortable to wear in any way? [0:05:46.6]

**S2:** No. No, the brace was great. I really liked it, actually. It was more uncomfortable to take it off than, like, to put it on, honestly. [0:05:54.5]

**S1:** What do you mean by that? [0:05:56.6]

**S2:** Because, like, I don't like I don't even know if this is like, medically right. I don't even know why this is. But, like, when I put it on, I guess, like, I just get used to it, like I would start to, like, fill it in and it would, it would like, like I would just mold to it. Right. And so when I took it off, it kind of hurt to like, go back to like, crooked position. Oh yeah. [0:06:19.3]

**S1:** Gotcha. And did you wear it while sleeping as well. Did that all the time. Did that ever feel uncomfortable. Like when you were sleeping? [0:06:29.0]

**S2:** It did at first, but I got used to it pretty quickly. Gotcha. [0:06:34.0]

**S1:** And did you like playing sports or doing anything like active during this time? [0:06:39.2]

**S2:** So when I was 12, we went on, like, a trip to, like, the Midwest. And so, like, we did a lot of, like, hiking and stuff, and it did kind of stuck to where when you were hiking, just because I went out of breath really quickly because it was like tight. Right? But, it it wasn't like terrible. Like, I if it really hurt, I could just take it off. But again, like, it hurt when I took it off. So I really I couldn't if I had to take it off, that meant that kind of meant I couldn't like hike that much more. Gotcha. Yeah. [0:07:10.8]

**S1:** So what about like, during your day to day life? Like, was there any moments where you were like, oh, this is really uncomfortable or like, I really don't want to wear it? I know you said like, you enjoyed wearing it, like almost all the time, but like, were there any, like, specific moments that you recall? [0:07:27.5]

**S2:** Okay. Like at school, it could be a little just so like. Okay. Oh. Oh my God. Okay. When you go to, when I had to go to the bathroom and I had to, like, unstrap the loud Velcro straps, I was really, I did not like that just because it was so loud. It was really loud to take it off. [0:07:45.7]

**S1:** Yeah, I can, like, hear the sound in my head right now. Like, I know exactly what you're talking about. [0:07:50.7]

**S2:** So, yeah, that that was not good. And also like, if it ever made a noise like in class, like sometimes when, like if I was leaning on it and it like fell off the chair and made like a really loud sound and that. No like, but other than that it was fine. [0:08:07.4]

**S1:** And like what about like in the summertime maybe I know it gets like a little bit hot inside a brace. Like was that ever like a problem. [0:08:15.2]

**S2:** Not really I yeah it was, it was fine. (..) All right. [0:08:24.5]

**S1:** Is there anything else like that you remember really clearly about your time while bracing that like you want to talk about? (..) [0:08:31.9]

**S2:** No, no, I don't think so. [0:08:38.6]

**S1:** Yeah, I know it's hard to like, remember, because it's been a couple of years. [0:08:41.9]

**S2:** Yeah. [0:08:43.0]

**S1:** But do you, like, think that wearing a back brace is, like, impacted your mental health in any way? [0:08:49.5]

**S2:** No, not really I yeah. I didn't really mind it. Okay. [0:08:57.2]

**S1:** Or like, do you think there could have been anything done differently to maybe like, I know you said you wore it like almost all the time, but like something to maybe, like make you, like, wear it for longer. [0:09:09.1]

**S2:** I guess if like, okay, like, I'm not gonna I'm like, I didn't think this was a huge deal. So I don't think like, yeah, I don't think it really like it like deterred me from wearing it. But it was a little bit ugly. Okay. I won't lie about that. So if it was just like a little bit less obtrusive, then yeah, I would, I would worn it like never taken it off basically. Yeah. [0:09:37.4]

**S1:** Did you ever like I know these were something like I was looking into while I was bracing but like go to like a scoliosis support group or anything like that. [0:09:45.5]

**S2:** I looked at a couple, but they kind of all sucked, like most of them were dead by the time I like, looked at them like curvy girls. It was dead. And yeah, a couple other ones. [0:09:55.8]

**S1:** Do you think you would have, like, benefited from one of those? [0:09:59.6]

**S2:** I think I would have benefited honestly from one that from, like just a group that gave me outfit tips like that was really the only thing I wanted. But, but everything else, like, I like, I didn't really feel the need to like, talk about, like. Or. I mean, yeah, I think it would have been nice. (..) [0:10:22.8]

**S1:** And the pain that you were talking about when she would take it off, was that just kind of always present after you, like after you take off your brace or would it come and go? [0:10:32.4]

**S2:** It would come right after I took it off and last for like maybe 15 minutes or something. And then afterwards, like, I would was, like, visibly more crooked, like I. Yeah. Gotcha. But it. And it kind of felt like nausea. Like I'm it. Yeah. It was like not good. Okay. [0:10:56.3]

**S1:** So that I can imagine that was comfortable. So that kind of like kept you wanting to wear the bracelet a lot. [0:11:01.8]

**S2:** Yeah. But honestly, if it. But since it went away like shortly afterwards I it was kind of either like I wore it all the time or I didn't like, wear it at all to avoid pain. Gotcha. Okay. [0:11:18.3]

**S1:** And before you started like this entire journey, like your scoliosis, did you really know anything about scoliosis? [0:11:26.1]

**S2:** Not much. No, I'd heard of it, but I didn't really know what it was. [0:11:32.2]

**S1:** So then when you were first diagnosed, like, how did that make you feel? [0:11:39.5]

**S2:** I was. Honestly, I didn't really feel anything. I was kind of stoic. Yeah. [0:11:45.7]

**S1:** And, you know, like, a little like, why don't you tell me a little bit about, like, your understanding of scoliosis? [0:11:51.4]

**S2:** No. I know what it is, I guess I know, like. How to treat it. The eye and. Yeah. Beyond that not really that much. Yeah. When I'm like yeah I know that. Like I know like you know like how different curves are treated and I know that I don't, I don't need any treatment anymore. But just basically the most important thing to me. [0:12:21.5]

**S1:** When like you were told oh like you need to start wearing a back brace. What was kind of like how, how were you told that I guess like would they tell you like what would happen in the future if you didn't? Or how did that conversation go about if you remember it? [0:12:36.6]

**S2:** Well, my mom told me and so and she, like, basically just explained, like, oh, if you don't wear this, you're gonna get surgery, and surgery is really bad, so you better wear it. And so yeah. And then and then the lady who did my back brace was like really, really nice about it. So it was. Yeah. [0:12:54.5]

**S1:** So how was that experience? Because I know that getting at least in my, in my experience, like getting fitted for a back brace isn't the most comfortable. Thing in the world. Yeah. So how did how did that go for you? [0:13:08.1]

**S2:** No, the lady who did it, it was a woman, first of all, which is pretty important to me. And then also, she it was like, fine, like she she didn't even touch me. She used, like, a scanner. So, yeah, I'm like, I'm so glad that I had her because she was really great about it. [0:13:24.4]

**S1:** That's great. I'm really glad to hear that. (..) Is there anything like about your scoliosis journey that if you could go back and do it over again that you would change or you'd wish happened differently? (..) [0:13:39.8]

**S2:** Oh, I probably should have done more like physical therapy at home. I, I went to the sessions, but then I didn't really do anything at home. So yeah, that wasn't great. [0:13:54.8]

**S1:** This session. Did you find like how did how did that work? Why don't you tell me a little bit about that? [0:13:59.9]

**S2:** Well, we had to, like, go all the way to the city for our session, so that was like a 45 minute drive. And, then the session, it was just like, some normal stuff. Like, I didn't really do a lot of, like, sports or anything like that. So it was actually kind of hard for me. But I think for like most people it would have been fine. It's just normal exercises like planks and stuff. [0:14:21.5]

**S1:** And were those like helpful with like the pain or like how, how would they help if they did. [0:14:28.7]

**S2:** No I, I didn't notice, they didn't really help with the pain or anything. I know they were supposed to make me like they were supposed to like help now I guess after bracing. But yeah, I didn't really do any of the exercises, so I don't think they really had much of an impact. [0:14:46.3]

**S1:** Gotcha. And, I know it's a little weird since, like, your mom played a really big role in your, like, your bracing and all of that. But are you satisfied with, like, your health care providers throughout, like, your entire bracing experience? [0:15:03.9]

**S2:** So like all of them, except, like, except the guy who did my act. Like, I'm not gonna. You probably know him, honestly, but, Yeah, the guy who did my exit just kind of like, I didn't really like him, but everyone else was fine. [0:15:20.1]

**S1:** Can you explain, a little bit about, like, your experience with the guy who did the x rays, if you don't mind. [0:15:25.7]

**S2:** It was just, like, uncomfortable. It's not like he was creepy or anything. It was fine. It was just, like, kind of uncomfortable just to, like, I don't know, like. Yeah, that was honestly the x rays. I think it was just because the x rays were the most invasive part of the whole thing. Honestly, like the the lady who did my brace was so, so nice about it that I was just kind of like, I don't know, it was just kind of like, shocking to like, you know, have to do an X-ray. [0:15:52.5]

**S1:** And it was just like, while while doing the x rays, was that the uncomfortable part? Like the positioning and all that or. [0:16:00.2]

**S2:** No, it was like, he would like, do like, I don't I don't really know what it was, but like, checkups before and after and it was. Yeah, that was not comfortable for me. Like I basically just had like lie down on like a table and he would like, I don't know, like. Do little like taps on my stomach. It was like like I feel like he did. He did like, very routine things. But it was. Yeah, it was kind of uncomfortable. That's it. [0:16:24.6]

**S1:** Yeah, yeah. I can't imagine that would be comfortable at all. Would you say, like, maybe if that was a woman doing that, like, would you have felt a little bit more comfortable or do you. [0:16:34.6]

**S2:** Oh yeah. Yeah, sure. [0:16:37.5]

**S1:** Yeah. Did that ever, like, make you not want to come in for your checkups? Like knowing that that was what was coming like those x ray. [0:16:46.0]

**S2:** Oh, well, I, I didn't like them, but I knew I had to do them, so I didn't really make a fuss of it. [0:16:52.8]

**S1:** Gotcha, gotcha. I'm sorry. Let me just take a look at my notes over here. Are there any like, activities that you really like, felt like you couldn't do in your brace that you really missed doing? [0:17:10.6]

**S2:** I don't I don't like play sports or anything like that. So yeah, I didn't really have that experience. And, (..) It. (..) No, I didn't really do anything that like I couldn't do in the race. I still don't, so. [0:17:28.0]

**S1:** That's good. I'm glad that, like, you felt like you could still do, like, everything that you wanted to. Yeah, I can't like. Yeah. I feel like there was something that you really wanted to do and you couldn't like. I can't imagine that would have been fun. [0:17:42.1]

**S2:** I mean, I have to say, I could, like, I took the brace off if I ever wanted to, like, do exercise, but I barely exercise those, like, not a big deal. (6) [0:17:59.7]

**S1:** Yeah. Is there anything else you want to talk about? Like about your, racing experience that you want to share with me? (..) [0:18:11.2]

**S2:** No, that's pretty much it. [0:18:15.3]

**S1:** All right. Well, thank you so much for answering all of my questions. It was really helpful. And if there's anything that you ever want to talk about, we're always here. [0:18:24.4]

**S2:** Okay. Thank you. I. [0:18:28.2]