**2025 SMA Adult Activation Qual**

*R01 Transcript
3:00pm*

**Moderator:** I'm seeing you're a Buckeyes fan. Do you live in Columbus, or did you go to school there or have a kid who went to school there?

**Respondent:** Well, we used to live in Ohio. We moved to Georgia about sixteen years ago. I went to Ohio University, not the Ohio State.

**Moderator:** A liberal arts school?

**Respondent:** Yeah.

**Moderator:** Interesting.

**Respondent:** They didn't have a football team, so you grow up with the one that has a football team. I mean, they had a football team, but just not a very good football team.

**Moderator:** Yeah. That's an important distinction. I actually used to work out with a woman who I became very dear friends with. She was the captain of her field hockey team at Ohio State, and it was my first entrance into superior athlete land. I just never grew up where I was, and her husband played for the baseball team. Remarkably driven human beings. Anyhoo, thank you so much for joining. Let me give you just my intro, and then we can just get to talking. It's really nice to meet you. I'm an independent market researcher. This is what I do for a living. I ask people typically somewhat nosy questions, and then you usually don't ever have to see me again. So, part of what makes the nosiness a little bit more tolerable is that I have no idea who you are, and we'll just keep it that way. So don't tell me your last name or the name of your doctor. I don't know what your phone number is or how to contact you or who you are beyond Michael who went to Ohio University. I do have a few colleagues listening in who just really want to understand everything I'm going to ask you about your journey with SMA. We are recording, but it's just for research purposes. Your name doesn't get attached to that or anything like that. Everyone's here just to learn and to understand your experience.

**Respondent:** I'm an open mic. I'm not really too concerned about any of that, but I appreciate it.

**Moderator:** Okay. Good. Two last things I'm required to say. One of them is my most formal thing I will say is that if by any chance you mention that you've had a less than ideal experience on a medication that my client makes, I have to write up what's called an adverse event report, and I might ask you some additional questions about that.

**Respondent:** Okay.

**Moderator:** Finally, you are my first interview in this study. Sometimes what happens in the first interview, like, I'm sorting out the timing just to be completely transparent. What'll happen is that I'll sometimes be going down, I really want to understand. Also, I'll look at the time and say, oh, no. I need us to keep moving, and then I might interrupt us and move us along. So this is my upfront blanket apology for any of my interruptions. Are you good with everything?

**Respondent:** Gotcha. I'm good with that. Just cut me off.

**Moderator:** Thank you. Okay. So can you tell me a little bit about yourself? Like, how old you are, if you live with anybody, how you spend your days, just so I have a sense of who you are.

**Respondent:** Yeah. So I'm 50 years old. I'm married. We have two kids, but the kids are from a previous marriage, but I've been in their life. Corona was three, Jaden's eight months. They're now 24 and 22, out of the house. We have a little dog, a little Morkey. I just quit working back in October 2024. So my days are now filled with a lot. I walk the dog every day, sort of fiddle fart on the computer, might watch stuff, I read a lot. No longer the corporate hustle and bustle anymore.

**Moderator:** Wow. What kind of work did you do until a year ago?

**Respondent:** I was a service manager for a telecom company. I was like a customer advocate liaison between the technical team and the customer, normally the director or VP level.

**Moderator:** Wow. Okay. That sounds like a high-pressure job.

**Respondent:** No.

**Moderator:** Because if there's anything wrong with anyone's digital or telecommunications in a company, that's very stressful. What prompted you to stop working?

**Respondent:** My upper body is now being affected, so I was struggling to type. I tried doing text to speech, and I just could not reinvent the wheel. I just couldn't keep up. I'm a perfectionist at heart. I used to be an A player. I started to fall back into a B minus C player, and that wasn't good for me.

**Moderator:** Yeah. Are you on disability at this point?

**Respondent:** Yeah. So I just went on my employer's long-term disability, and then I just got approved from Social Security disability, like, a month ago.

**Moderator:** Congratulations. I know it's maybe a mixed bag on the congratulations, but...

**Respondent:** It could be worse. Right? There could be nothing, so I'm grateful.

**Moderator:** Yeah. So I have written down that you're type three SMA. Is that correct?

**Respondent:** That's correct.

**Moderator:** Okay. So when were you first diagnosed with SMA? How old were you?

**Respondent:** I was around 10 or 11 years old. I don't remember the exact date and time. There was a little bit of trying to figure out what was going on with me. I kept on falling down when running, not all the time. It was just my right leg that would give out. So then that started doctor's appointments. About a year into that journey, I saw a doctor that said you're showing all the signs of muscular dystrophy, which then led me to the Ohio State University and a doctor Mendel, who was a leading pioneer in that, and then diagnosed me officially.

**Moderator:** That's so interesting. I think I meant to ask you not to say any doctors, which is totally fine. Who knows if that doctor's even practicing, right? It was forty years ago. So that's not really crass, but that's fascinating. Right? Because it seems so long ago, forty years in terms of SMA and development, stuff like that. So interesting. How is your... I mean, you just talked about sort of things evolving for you. But how would you describe the role of SMA in your life now? Just talk to me a little bit about SMA's impact in your life.

**Respondent:** Where it's affecting my life now is just my day-to-day abilities to do meaningful activities. My wife gets me in and out of bed. She dresses me. Up until recently, she was bathing me. We recently just got a caregiver about a month ago that comes in and bathes me and helps me with little things around the house. You know, as a man, I'm a fix-it guy, and I look around and I can't fix anything. In fact, when I try, I end up causing more issues. So that's frustrating. Quality of life is diminished a lot.

**Moderator:** Thank you for sharing that. When did you start to lose more of your... I mean, you talked about your upper body struggling with your upper body to get stuff done at work. When did that evolution happen? I don't know if it was a slow process over time, or was there a certain moment?

**Respondent:** No. It's been slow. I've never been super strong in my upper body, but I mean, I've been stronger than most. I would say probably over the last six or seven years, it's just started to get worse and worse. It's hard to track it day to day. You look back on it, like, a month or a couple months, and it's like, oh, I'm doing it different, or I'm not doing it at all, or I'm avoiding it.

**Moderator:** Wow. So you don't track it, number one, but it's not necessarily something you see changes day to day, but over a couple months, you can see differences.

**Respondent:** Yep.

**Moderator:** Broadly, how would you describe your current health, Michael?

**Respondent:** Everything but SMA, I'm as healthy as anyone. I have my regular physicals, and I mean, my doctor says I'm in great health, but you have muscular dystrophy.

**Moderator:** Wait. Muscular dystrophy?

**Respondent:** Or spinal muscular atrophy. My doctor does that. It's sort of funny that they don't really know the intricacies of the different diseases, so they just sort of lump it in as muscular dystrophy.

**Moderator:** That's interesting. How does that make you feel? How is that for you, the doctor not really understanding the intricacies of SMA?

**Respondent:** I think it used to bother me until I really understood what health care is. A doctor can't know everything, especially a primary care physician that's more treating your immediate needs, like a rash or this, that, and the other. So having a very unique situation, it doesn't bother me as much. But when I was younger, looking at doctors as they're supposed to be the experts, they're supposed to know. And then you get a little bit older and wiser and you realize, no, nobody can know everything. So I cut them some slack nowadays.

**Moderator:** That's so interesting. Speaking of doctors, who are you seeing, if anyone, for specifically SMA-related care? Do you have an SMA team?

**Respondent:** Well, no. I have a neurologist who is in the world of SMA. I sought her out several years ago. I wasn't seeing anybody for a long time specifically. But when I started to get wind of possible treatments, that's when I was like, I need to associate and get connected. But I don't see her on a regular basis. I was doing a case study, which I had stopped doing, and she knew the doctor that was leading some of that case study. She would come over and visit and do some of the testing when they needed a neurologist or somebody to do that testing. So I wouldn't have an appointment with her, but we would catch up. I haven't officially gone to her office in probably three years at this point.

**Moderator:** Okay. When you say case study, I'm familiar with the language clinical trial. Is that what you mean?

**Respondent:** Yeah.

**Moderator:** Okay. So you said you weren't seeing anyone for a while. When were you last seeing a neurologist regularly? What when was that?

**Respondent:** To be honest, I was never seeing a neurologist on a regular basis. When I got diagnosed at a young age, right, 11 or 12 years old when my official diagnosis came in, I went into denial. I was still playing sports. I was still active. I did not want to hear what they were telling me was going to happen. I avoided doctors like the plague. I then went back to a neurologist when I graduated college. I was 24 years old to see if there were any changes. When I was young, I had asked what should I be doing? Should I be on a diet? Should I be exercising? The answer I got when I was young was we don't know. Try it and tell us. When I went back at 24, here's almost twelve years later. I went back and I got the same response. The only thing they did different when I was 24 was they did a genetic test to confirm and verify because before I had a muscle biopsy that confirmed what I had. At 24, they did the genetic test, and yes, you have spinal muscular atrophy type three. They were able to zero it in. But since they couldn't give me any hope of what to do, I didn't want to wrap myself up into doctor appointments.

**Moderator:** Yeah. And I was young and ambitious, and I wanted to make money, so I worked. Then I did not go back to see a neurologist until 2017 or 2018.

**Moderator:** Let's pause there for a second because you alluded to this, but I want to make sure I understand what motivated you to go back. First of all, it's very compelling what you just said earlier. I wish I had four hours to talk to you because you're very articulate, and you have a really interesting story. Thank you so much for taking part in this. It's been so helpful already.

**Respondent:** Okay. Great.

**Moderator:** But it's striking what you just said. The combination of denial and not getting any hope from the medical community didn't feel like there was anything they could do for you. So what happened in 2017 and 2018 that prompted you to go back to the doctor?

**Respondent:** I was aware of a particular treatment, but I did not like the way that it was administered. That was not something that I wanted to go down.

**Moderator:** Can you tell me more? Can you pause there and tell me a little bit more about that?

**Respondent:** There was a drug called Spinraza, and you had to get a lumbar puncture for it. I wasn't comfortable with the way that it was being administered. But I had started to hear that there was something on the horizon about an oral medication called Everesti. I was like, well, if I'm going to be able to get this prescribed, I need to get aligned with a neurologist because my primary physician, who just lumps everything together as muscular dystrophy, was not going to be able to help.

**Moderator:** Okay. Let me pause. I'm sorry I keep pausing you, but everything you're saying is interesting. It's a problem. You're too interesting. So it's striking that you said in 2017 that you were aware of treatment and also that you're saying that oral was on the horizon. So you weren't going to a doctor. How were you learning about these developments in SMA treatment?

**Respondent:** Through Facebook. That was the only thing that I was getting my information from, these Facebook support groups that I was a part of for spinal muscular atrophy.

**Moderator:** So interesting. When do you think you joined those groups? Do you have any memory?

**Respondent:** I can't remember. I don't think I joined until either my very late thirties or my early forties. I've only been on it for probably ten years, maybe eleven at the most.

**Moderator:** Okay. So mid-2000s, like, 2014 or '15-ish.

**Respondent:** Yeah.

**Moderator:** What prompted you to take part or to visit those Facebook groups? How did you feel about those groups?

**Respondent:** That's a difficult one as well. Just on the basis of I've tried to not associate myself with the disabled community. But obviously, my reality was becoming that I am part of the disabled community. It was sort of me tiptoeing into that without fully being in it. I went to a face-to-face support group. This was I can read about it and sort of see what other people are doing about it. If I want to click to see what these people look like, unfortunately, that's how I was sort of getting used to the idea that, wait a minute, this is where I'm headed.

**Moderator:** Can you tell me a little bit about why you were trying to keep all of this at arm's length? What did it feel like? What were you trying to avoid?

**Respondent:** Prejudice around it that I had of myself. I had an early experience as a kid, prior to all this going down, of hearing how people talked about disabled people. I knew that was part of my denial that doctors told me I was going to be like that as well, and then not wanting to be perceived that way and being ridiculed and looked down upon. In turn, I had it myself, which was sort of ugly of me.

**Moderator:** I appreciate your honesty. Was there a specific event or a specific set of events that you remember in terms of the people?

**Respondent:** I have a weird family dynamic, but my adopted father, he wasn't my biological dad, but my adopted dad married my mom. We were driving down the road, and there was a gentleman in a motorized wheelchair coming down the sidewalk. I was in my early teenage years, and he was bumping on the sidewalk. My dad made an off-colored joke. That really struck me knowing that I have this disease. I don't even know if he was even aware of it. It just came out. It wasn't an apology; it just was what it was. I don't blame him; he was raised in a certain way as well. It was common to make fun of people less fortunate because it's funny, but it's not funny.

**Moderator:** When you were diagnosed at eleven, ten, eleven, twelve, how was it described to you? Do you remember?

**Respondent:** Before I was told I had SMA, my primary care physician in Ohio knew somebody. He was asking around trying to find out what was going on with me. He couldn't figure it out, so he sent me to a doctor at a local university where we lived. That doctor described that he said this. Basically, he had no bedside manner whatsoever. He said, you're showing all the signs of muscular dystrophy. You're going to be confined to a wheelchair with no movement from the neck down before you graduate high school. I'm sorry to be blunt, but I just want you to accept or get ready for what's to come. This is now time to start planning and making the decisions your family needs to make. I had my adopted dad and my stepmom sitting there, both uneducated, and it was like, wait a minute. I just got done with baseball practice. It was hard. It was very hard. There was no bedside manner whatsoever. I think he was trying to, in one sense, look, I'm not going to beat around the bush. I'm not going to give you hope. It's time to just swallow the hard truth. Now let's move forward. But as a kid, that was hard.

**Moderator:** Sorry. Sometimes when things are just so hard, I have to just pause for a second. It's just so intense. You've described these lows that you're receiving, but then you're also describing yourself as this incredibly remarkable young person, right? Like, going to this great university and being very ambitious and even going to football games. I mean, you're... I'm hearing these two things at the same time, and it's striking.

**Respondent:** Yeah. I truly believe the reason why I was able to do what I've been able to do is because of my denial and stubbornness that I was not going to fall victim to what they're classifying and say I was going to be. I think if I would have listened to what they said and internalized that, I think I would have become worse off quicker, and I don't think I would have achieved anything that I've achieved.

**Moderator:** So for you, a lot of your health, you attribute to keeping SMA at bay in some ways, like keeping some separation between you and involving yourself in this disease.

**Respondent:** Yeah.

**Moderator:** It's also striking. So you start going to these Facebook groups. Do you remember what led you to go to these Facebook groups? Because I'm very interested in the fact that it was knowing that there's treatment available that was clearly significant for you. But there's a step before that.

**Respondent:** I don't know if I joined them before or after, but one of the changes that occurred when we moved to Georgia, we went to an abilities expo type conference that had different things. The type of wheelchair that I was in, there was a gentleman that was in the same type of chair that was very interested because of the wheelchair I was in. He was trying to promote power wheelchair soccer. My wheelchair was the type that is very good for that sport. He wanted to buy my chair from me and get me to play power wheelchair soccer. Through that, I started to get on Facebook, and I'm thinking that's when either through connections with them that maybe that popped up that you might be interested in the support groups because he and some of the other players were in these groups. I'm pretty sure that's sort of what happened.

**Moderator:** And when did you start using a wheelchair? How old were you when you were?

**Respondent:** I started... I got one right after I went to a community college right out of high school, but then I went away to a major university right before I turned 21. I transferred, and that's when I got the motorized wheelchair because the college I went to was basically built on a hill. But I wasn't using it full time. I would literally ride the wheelchair to class, park it outside the classroom, stand up out of the chair, grab my cane, and walk in. It never went in with me. I wanted to show everybody that I'm not the chair. I didn't start using a chair constantly until I had a leg break when I was 34 or 35. Then another one, and then another one, and then it sort of led me. So I've been confined to the wheelchair for about eight or nine years now.

**Moderator:** How did you feel when you're on these Facebook groups? It sounds like you were initially kind of a lurker. Is that a fair word?

**Respondent:** A little bit, yeah. I still might be a lurker. Sometimes I'll post, but most of the time, I'm just looking, observing, reading.

**Moderator:** Me too. Most of us. And then there are those people who overpost and you're like, dude, don't you have any sense that you're sharing this face?

**Respondent:** Yeah.

**Moderator:** How did you feel reading about SPINRAZA? I guess you probably first started learning about it. Tell me about when you first started hearing about treatment for SMA on those Facebook groups. That's very important to me to understand how that made you feel.

**Respondent:** It made me feel hopeful that, wait a minute. Because for so long, I heard that there's nothing. They didn't even know what was causing it. Then when they were able to identify what the cause was, it was like, well, it took them this long. There's never going to be anything. Then I hear that, wait a minute, we've found something that stops the progression. It started to make me feel hopeful. If I can get comfortable with where I'm at today, if we could just stay like this, okay, I can function the rest of my life like this. I'm doing it now. This is good. I don't... I've gotten pretty bad, but at least at that point, I was still driving. I was still working. There was a lot of stuff that I was still bathing on my own. So it was a lot of hope. But with the administration of it with Spinraza, I just did not like... I don't know why I was so against it. I think because I just want something that's non-intrusive, that's easy. I don't like spending a lot of time at doctors. I want to live my life. When I started hearing about, oh, there's something you could just take, it was like, oh, I take medicine at night for pain and to help me sleep, and I take vitamins. I'll swallow a pill all day long or I'll take cough syrup. So when I started hearing about Everesti, I was like, okay, this is something I can get on board with.

**Moderator:** Okay. I had written down here that at some point in your history, you have taken both Everesti and SPINRAZA at some point. Is that accurate?

**Respondent:** I was part of the clinical trial that I just was a part of for the past year and a half.

**Moderator:** Alright. Okay. So when did you take Everesti liquid from one to one? Do you happen to remember?

**Respondent:** So I've been on it on two separate occasions. The first time, I started in April 2021, and I took it until April 2022.

**Moderator:** Wow. Okay. Twelve months.

**Respondent:** Yep.

**Moderator:** Mhmm. And then I stayed off of all medicine from that time until, I think it was more like May 2023. Then I stopped it in December 2023 and started the clinical trial with SPINRAZA in December 2023.

**Moderator:** Was it any particular... I mean, given that Spinraza was already out, was it a certain kind of Spinraza with a clinical trial?

**Respondent:** It was the double dose of Spinraza.

**Moderator:** Okay. And the reason I started Everesti again was that the clinical trial was based on having been on Everesti. They wanted to see what the transition would be from Everesti into the higher dose.

**Moderator:** Just to be clear, you were on Everesti from '21 to '22 for a year, had a year of no treatment, and then started the clinical trial in December '23 for the higher dose of SPINRAZA?

**Respondent:** Yes.

**Moderator:** And how long were you on that clinical trial with the higher dose of SPINRAZA?

**Respondent:** Up until April, my last dose of that I participated in was April.

**Moderator:** Wow. Okay. So, like, fifteen months.

**Respondent:** Yeah.

**Moderator:** And you're not on anything right now?

**Respondent:** No. I'm not on anything. I decided not to continue with the trial.

**Moderator:** Oh, there was a... did you opt out?

**Respondent:** I could have kept doing it. I'm a non-responder to that medication. It did not keep me stable. I continued to digress the entire time. There was no change. I actually got worse.

**Moderator:** Okay. Alright. So, again, 2017, 2018, you're aware. It's interesting initially that you were so averse to the lumbar puncture. Obviously, you then did that for a year. Any thoughts about back then, what was the major... like, for you, and maybe why it was different later?

**Respondent:** I think the big part was I was just a workaholic, and I didn't want to take the time off, the travel, to have to transfer to possibly have any adverse effects, which I did have a little bit of that once I did start taking it. I didn't realize what the adverse effects were. But I just didn't like the fact of putting needles in my back.

**Respondent:** My tune changed when I saw that a lot of people were having more stability on Spinraza. I had a different experience with Everesti, and it was even more... my interest was piqued because, oh, here's double the dose of this stuff that other people are saying they're having more stability and actually maybe more gains on Spinraza than Everesti.

**Moderator:** So your perception of the costs and the benefits shifted. Number one, you heard the benefits being brought more in your face. You were sort of seeing them with your peers. And you saw that maybe even you could get double that or something like that.

**Respondent:** Yeah.

**Moderator:** Okay. Alright. And to be honest, I had reached back out to the neurologist to see if I could get back on Everesti after that year hiatus anyways because I wanted to see if I could get the same boost because I got one hell of a boost from it the first time I was on it. I wanted to see if I would get that boost again, but we were running up against insurance denying it. What's funny, or not funny, or coincidental, is the day that I looked into the clinical trial is the day that my advocate for Everesti called and said, hey, I know you didn't want to pursue this anymore because you got denied twice, but we kept pushing and you got accepted. The trial needed me to be on it in order to get accepted for the trial. I look at that as a coincidence that maybe this is something I need to do.

**Moderator:** What do you mean maybe this is something?

**Respondent:** Well, whatever your beliefs are, right? Okay, God, is this a sign that you're giving me something that I need to realize I'm going downhill and all the stars just aligned? Okay, I'm just going to go forward with it.

**Moderator:** So just to be clear, did you go back on Everesti in order to get in the trial?

**Respondent:** Yes.

**Moderator:** So in April or May '23, I started taking Everesti again. I had to be on it for six months before I could start the Spinraza trial.

**Respondent:** Yeah. That's why I said I've had Everesti twice.

**Moderator:** Okay. Got it. Got it. Okay. And how did it go for you the second time you were on it?

**Respondent:** The second time, I didn't get the boost that I did the first time. The first time when I took it, I literally had stopped driving my accessible vehicle several months prior. I started taking it that first time, and within a month and a half, I was strong enough to start driving again. I was able to wash my hair again. It was like, oh my gosh, this is amazing. But then what happened is after six months, it's like the bottom fell out, and I got worse quickly. It was devastating, and I couldn't... it never rebounded.

**Moderator:** Wait. When was that?

**Respondent:** That was the first time I took Everesti in April 2021.

**Moderator:** So at the six-month point, the first time after you've taken Everesti for six months, you sort of bottomed out. You had peaked and bottomed out still while you were on Everesti.

**Respondent:** Yeah.

**Moderator:** Is there... okay.

**Respondent:** Right. And then since there was no testing of my physical ability during that time, they just gave it to me. If they would have tested and saw the gains that I was having at two months, four months, even six months, and then tested to see that, oh, wow, he's really gotten weaker and dramatically weaker. When we tried to get it renewed, insurance called and said, well, he's gotten worse. This hasn't kept him stable. This didn't do anything. So I don't know if I would have stayed on it longer if it would have come back around. I have no idea.

**Moderator:** So just so I'm clear, I haven't even 100% got to how you got on Everesti, but we'll get there. So you got on Everesti in May in April '21. You had six months of remarkable progress, and then six months of it sort of bringing you back down to where you were before, kind of.

**Respondent:** I'm not even back down to where I was before. Worse than where I started it. That's what was so scary.

**Moderator:** So what prompted you to stop Everesti in April of '22?

**Respondent:** Insurance wouldn't pay for it. They wouldn't allow me to renew it.

**Moderator:** Oh, okay.

**Respondent:** There was part of me going, wait a minute. I got worse. The other part was like, well, insurance has denied it anyways. That's the writing on the wall. The stars aligned. You're telling me I need to stay off of it. I'll stay off of it.

**Moderator:** Interesting. And I know you just said you think insurance denied it because they did an annual baseline test and didn't see any progress. Is that your understanding of why they denied you at that point?

**Respondent:** My understanding, yes. That's what they had in the letter they sent back to me and the neurologist.

**Moderator:** It's striking to me that a couple points in your journey that I understand so far, you talk about how sometimes things are kind of like signs, right? Given that you sort of declined on Everesti and the insurance denied you, you sort of had that acceptance of, like, it was meant to be. Am I understanding that correctly?

**Respondent:** Yeah.

**Moderator:** Right?

**Respondent:** You get that.

**Moderator:** Please tell me if I'm misunderstanding because you also said something similar about another time that I can't even... I think it was when the insurance when Everesti called you back and said, actually, we accepted you for the clinical trial. So you're like, okay. So maybe this was also meant to be.

**Respondent:** Right. Because it all happened on the same day. What's the coincidence? I mean, okay, I've...

**Moderator:** Okay. If you think about the future and the possibility of these treatments for you, what or whom do you think will have the most influence on whether or not you actually go down the treatment route? It's going to require work for you because it's not already set up. You have a doctor who thinks you have muscular dystrophy who's in the groove. But if you're going to get SMA-specific treatment, you're going to have to find a doc. You don't even have a nurse practitioner. You're going to have to set it all up. You're going to have to go to a place that feels really uncomfortable. You might have to fight the insurance. What do you think would be the biggest help for you in accessing treatment? Say you decide on some level you would like to get treatment, but you wish it could be emotionally and logistically easier. What would make it easier for you in those ways?

**Respondent:** I don't see any change in how I have to go about it. So what would be the perfect scenario? I don't know. Have an educated primary physician that could just take the place of the neurologist. That would probably be the easiest route.

**Moderator:** I wonder about an advocate, right? It's interesting you described how the Everesti advocate called you and said...

**Respondent:** She still keeps in touch with us, which is cool. We would have conversations, and it was really helpful through the whole process of getting on Everesti. I don't think I would have gone down the rabbit hole if it wasn't for that. It was nice that I wasn't just a, oh, I got him on it and let's move on. She just continues to check in.

**Moderator:** Do you ever talk to her about the possibility of restarting the treatment?

**Respondent:** Yeah. I had mentioned to her that I had stopped doing the clinical trial and that I was hesitant about Everesti just based on the past scenarios that I've gone through. That's when she said, well, there's also another drug that's on the horizon of getting approved. You might want to look into it. I said, yeah, I've heard of it. That was it.

**Moderator:** It's so nice that you feel like she's in your corner.

**Respondent:** Yeah.

**Moderator:** I could not have asked for a better first respondent. I feel so lucky that I got to talk to you. You are so self-aware. It's striking. Thank you so much for sharing everything. I have no idea. I am actually married to a Gator, a Florida Gator.

**Respondent:** You gotta tell them that us Buckeyes aren't that bad. We're not that bad.

**Moderator:** I feel like I'm always listening to Michigan, Buckeyes, Gators. Even my 14-year-old son, when he uses the pronoun, he says, well, we. I was like, Harry, who's the we? He's like, the Gators, mom. I was like, oh, brainwash.

**Respondent:** That's funny.

**Moderator:** Listen. I wish you all the best. You've been so great, and thanks so much for your time.

**Respondent:** Yeah. Thank you.

**Moderator:** Okay. Bye.

**Respondent:** Bye.