**2025 SMA Adult Activation Qual Transcript**

*Oct 1, 2025 | 3:00 PM*

**Respondent:** Yes. I am.

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

**Respondent:** Well, so 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. Yep.

**Moderator:** Interesting.

**Respondent:** So 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. Right?

**Moderator:** Yeah. That's an important distinction. I actually used to work out with a woman who was the captain of her field hockey team at Ohio State, and it was like my first entrance into superior athlete land. I just never grew up where I was just and her husband played for the baseball team. It's 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.

**Respondent:** Okay.

**Moderator:** 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 Respondent who went to Ohio University. I do have a few colleagues listening in who just really wanna understand everything I'm gonna ask you about your journey with SMA. And we are recording, but it's just for research purposes. Your name doesn't get attached to that or anything like that. Just here. 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 mentioned 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. So sometimes what happens in the first interview, like, I'm sorting out the timing just to be completely transparent. And so what'll happen is that I'll sometimes be going down, I really wanna 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:** Okay. I got permission to cut you off.

**Respondent:** Yes.

**Moderator:** 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 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, I don't know, a lot. I walk the dog every day, sort of fiddle fart on the computer, might watch stuff, I read a lot. Not 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. So I sort of was like a customer advocate liaison between the technical team and the customer, normally, the director 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, you know, text to speech, and I just could not reinvent the wheel. I just couldn't keep up. I'm a perfectionist at heart. Used to be an A player. I started to fall back into, like, a B minus C player, and that wasn't good for me.

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

**Respondent:** Yeah. So I just got, I 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 like maybe a mixed bag on the congratulations, but...

**Respondent:** Yeah. 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, 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. So they and it was just my right leg that would give out. So then that started doctor's appointments. And 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 who was a leading pioneer in that that then diagnosed me officially.

**Moderator:** That's so interesting.

**Respondent:** Oh, okay.

**Moderator:** 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 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 sort of the role of SMA in your life now? And I don't know. 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 just about a month ago that comes in and bathes me and then 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 it'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, 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. But I would say probably over the last six, seven years, it's just started to get worse and worse and worse. It's hard to, you know, I don't track it day to day. It's like 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. Right?

**Moderator:** Wow. So you don't track it, number one, but and 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, Respondent?

**Respondent:** Everything but SMA, I'm as healthy as any, but I mean, I have my regular physicals and all that. And I mean, I'm just she was like, you are, I mean, in great health, but you have muscular dystrophy.

**Moderator:** Wait. Muscular dystrophy?

**Respondent:** Or spinal muscular atrophy. My doctor does that. My primary care physician, 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? Your primary sort of 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 sort of immediate needs of, you know, a rash or this, that, and the other. So having a very, I know I'm very special. Right? I have a very unique situation. So it doesn't bother me as much. But when I was younger, looking at the medical, I guess, looking at doctors as they're supposed to be the experts. They're supposed to know. And then, you know, 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 for health care providers for SMA-related care? Who makes up your SMA team?

**Respondent:** Well, no. I have a neurologist that she is, in the world of SMA. So she knows and 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. And so 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. So she would come over and visit and do some of the testing when they needed a neurologist or somebody to do that testing. So then I would have, I wouldn't have an appointment with her, but we had an appointment. Right? It was we would catch up on but 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:** So to be honest, I was never seeing a neurologist on a regular basis. So when I got diagnosed at a young age, right, 11, 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 what was going to happen, and so I sort of 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 or, you know, and when I was young, I had asked what should I be doing? Should I be on a diet? Should I be exercising? This, that, and the other. And the answer that I got when I was young was we don't know. Try it and tell us.

**Moderator:** Yeah.

**Respondent:** And so when I went back at 24, here's almost, like, twelve years later. Right? I went back and I got the same response. The only thing that they did different when I was 24 was they did a genetic test to then confirm and verify because before I had a muscle biopsy that confirmed what I had. At 24, they did the genetic test was, you know, 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, why I didn't want to wrap myself up into doctor appointments.

**Moderator:** Yeah.

**Respondent:** And I was young and ambitious and I wanted to make money and so I worked. Then I did not then go back to see a neurologist until, that would have been 2017, 2018.

**Moderator:** And let's pause there for a second because you I think you alluded to this, but I wanna 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, like, four hours to talk to you because you're such, first of all, you're very articulate, and you have a really interesting story. So I'm so thank you so much for taking part in this. So helpful. It's been so helpful already.

**Respondent:** Okay. Great.

**Moderator:** But it's striking what you just said. Like, the combination of denial and not getting any hope from the medical that didn't feel like there's anything they could do for you.

**Respondent:** Right.

**Moderator:** So that okay. And yeah. And maybe there was even sort of negative association with going okay. Alright. 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. I that was not something that I wanted to go down. But I had started to hear that there was something on the horizon about an oral medication. So and that's called Evrysdi. And so 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, he was not going to be able to help.

**Moderator:** Okay. Let me pause. Okay. I'm sorry I keep pausing you, but everything you're saying is interesting. It's a problem. You're too interesting.

**Respondent:** Okay.

**Moderator:** 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 are you learning about these developments in the SMA treatment?

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

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

**Respondent:** That I can't yeah. I don't know.

**Moderator:** Do you think you were in your twenties, your thirties?

**Respondent:** No. I would relate Bloomer to the whole Facebook thing. I avoided it like the plague.

**Moderator:** Yeah.

**Respondent:** I don't think that Facebook was around when you were in your twenties anyway, so...

**Moderator:** No.

**Respondent:** So I think I didn't join until either my very late thirties or it would have been 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.

**Respondent:** Yeah.

**Moderator:** Ish. What prompted you to take part or, you know, to visit those Facebook groups? And what was your 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 disability disabled community. But, obviously, my reality was becoming I am part of the disabled community. So it was sort of me sort of tiptoeing into that without full-fledged being in it.

**Moderator:** Can you tell me?

**Respondent:** 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. And if I wanna click to see what these people look like, unfortunately, you know, that's how I was sort of getting used to the idea that, wait a minute, this is where I'm headed.

**Moderator:** Yeah. Can you tell me I can sort of guess from some of the things that you said, but if you don't mind in telling me a little bit about why you were trying to keep all of this at arm's length. What do you think what did it feel like? What were you trying to avoid?

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

**Moderator:** I just so 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 adopted dad. Married my mom. But anyway, so we were driving down the road. There was a gentleman in a motorized wheelchair coming down the sidewalk. I would've, I was early teenage years, and he was bumping on the sidewalk. Right? I mean, the little cracks in the and my dad made an off-colored joke. And it really just knowing that this is I have this disease and that and I don't even know if he was even aware of it. Just based it just came out. Right? And it wasn't I'm sorry or it would just was what it was. I don't blame him. He was, you know, raised in a certain way as well, then that was sort of common. 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, were you told you have a how was it described to you what SMA is? Do you remember?

**Respondent:** Well, so before I was told I had SMA, the way that I got up to the doctors that were more familiar with this, 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. And 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 gonna 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 basically 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. And then so I had my adopted dad and my stepmom sitting there, both uneducated, and it was like, wait a minute. We just 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 gonna beat around the bush. I'm not gonna give you hope. It's time to just swallow the hard truth. Now let's move forward. But as a kid, shoot. That was hard.

**Moderator:** Sorry. Sometimes when things are just so hard, I have to just pause for a second.

**Respondent:** Yeah.

**Moderator:** It's just so intense. Yeah. Because you've described these, like, lows that you're receiving. Right? 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 going even going to football games. I mean, like, 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 became it would have been 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 sort of keeping the SMA at bay in some ways.

**Respondent:** Yeah.

**Moderator:** Like, keeping some separation between you and sort of involving yourself in this disease and identifying with it. So it's also striking so you start you start going to these Facebook groups. Do you remember even what led you to go to these Facebook groups? Because I'm very I wanna get to the point that it was knowing that there's treatment available that was clearly significant for you. But there's a step before that, where you just Facebook groups.

**Respondent:** Yeah. So 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 thing, trade show that had, you know, different things. And 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. And so he was trying to promote power wheelchair soccer. And because of my wheelchair, my wheelchair was the type of ones that are very good for that sport. And so really what he wanted was to buy my chair from me. Right? And then he was trying to get me to sort of play power wheelchair soccer. And through that is when I was starting to get on Facebook, and I'm thinking that's when either through connections with them that then 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 that then I'm thinking that's what led me into going, oh, well, let me just go ahead and join or look or whatever. 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:** So I started I got one right 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, walk in. Wherever I went, it never went in with me. It stayed out. I wanted to show everybody that I'm not the chair. But then I didn't start using a chair constantly. I had a leg break when I was 34, 35.

**Moderator:** Okay.

**Respondent:** Then another one, and then another one, and then it sort of led me. So I've been sort of confined to the wheelchair for about eight, 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:** Yeah. A little lurker. I still might be a lurker. Right? I mean, sometimes I'll post, but I mean, most of the time, I'm just looking, observing, reading.

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

**Respondent:** Yeah.

**Moderator:** How did you feel reading about SPINRAZA and I guess you probably first start learning about tell me about when you first just started hearing about treatment for SMA on those Facebook groups. Like, 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. There is nothing they didn't even know what was causing it. And then when they were able to identify what the cause was, then it was like, well, it took them this long. There's never going to be anything. And then they hear that, wait a minute, we've found something that stops the progression, then 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. This is I'm doing it now. This is good. I don't you know, I've gotten pretty bad, but at least I've, at that point, I was still driving. Right? There was I was still working. There was a lot of stuff that I was still bathing on my own. There was a lot. So it was a lot of hope. But with the administrating of it with Spinraza, I just I 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, this, that, and the other. I wanna live my life. And so when I started hearing about, oh, there's something you could just take. It was like, oh, I take medicine at night for, you know, pain and to help me sleep, and I take vitamins. I'll swallow a pill all day long. Right? Or I'll take cough syrup. I'll take a liquid. That was so when I started hearing about Evrysdi, that was okay. This is I can get on board with that.

**Moderator:** Okay. I had written down here that at some point in your history, you have taken both Evrysdi, but also I've written down that you actually did have 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:** Oh, alright. Okay. So when did you let me just get these dates down. So when did you take Evrysdi 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, April or no. I think it was more like May 2023. And 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? Or...

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

**Respondent:** Yep.

**Moderator:** Mhmm. And then I stayed off of all medicine from that time until, April or no. I think it was more like May 2023. And 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? Or...

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

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