**SMA Adult Activation Qual Transcript**

Oct 6, 2025 | 3:00pm

**Moderator:** Good. Before we begin, I just wanna give you a quick introduction. I really appreciate you joining today, and we're gonna be talking all about SMA and SMA treatment in particular. Everything you say today is completely confidential. I do not I didn't even know your first name, and I don't know your last name, so let's just keep it that way. And, I don't please don't if you can, manage not to tell me the name of any doctors involved in the SMA treatment, that'd be great too. I do have a few colleagues listening in. They don't know who you are either, and we're recording just for research purposes. If by any chance you mentioned that you've had a less than ideal experience on a medication my client makes, I have to write up a little report called an adverse event report, and I might have a few questions to ask you about that. Also, I know I think you did you give, seventy five minutes of your time? Is that correct?

**Patient:** Yes, ma'am. Yes, ma'am.

**Moderator:** So even though that seems like a really long time, every once in a while, we're like, can we really talk to each other for an hour, fifteen minutes? Every once in a while, I still need to interrupt folks just to, like, hustle things along just because I do have. A ton of questions. Are are you okay with all that, everything I said?

**Patient: Yes** Ma'am.

**Moderator:** Any question? Okay.

**Moderator:** Will you tell me is it are you the person who has SMA, or are you a caregiver of someone who has SMA? Or.

**Patient:** I have SMA.

**Moderator:** You have SMA? Okay.

**Patient:** Yes.

**Moderator:** Can you tell me a little bit about yourself if you live with anybody else, how you spend your days, just so I have a sense of who you are?

**Patient:** Sure. I live with my children and my husband, and we have two, dogs. I spend my days I work part time for a local school, and I am enrolled in school to earn my bachelor's.

**Moderator:** Wow.

**Patient:** And, you know, I do all the other daily things in between there.

**Moderator:** That's that's a full that's a lot going on there. How old are your kids?

**Patient:** I've got 19, 17, and 15.

**Moderator:** Wow. Alright. You're full on yeah. I have this is not supposed to be me. I have one 16 year old and two 14 year olds. So, like, just behind you.

**Patient:** Yep.

**Moderator:** And what do you do, for the when you work part time for local school district, what are you doing for them?

**Patient:** I work for the front desk. So I, when the kids come in late or need to check out, I, you know, ensure that they're safely checked in or out and then input some data into the system, whether it be attendance or other various things that are assigned.

**Moderator:** That's great. And amazing you're getting your bachelor's. Are you what are you majoring in? Sorry. These are just, like, nosy questions. They're not crucial, but it helps me get to know you a little bit.

**Patient:** You're good. I actually I've got my associates in medical coding and billing.

**Moderator:** Interesting.

**Patient:** In medical office admin, So I thought it'd be fun to get my bachelor's in human resource management. Nothing together.

**Moderator:** I mean, it's all very there's a lot of detail in both.

**Patient:** Yeah.

**Moderator:** Right? A lot of systems stuff. Even like, I think about HR as, like, people, people, people, but it's a lot of systems too. Right?

**Patient:** Yeah.

**Moderator:** I don't Know. So well, good for you. So when your type your type three SMA. Is that right?

**Patient:** Yes, ma'am.

**Moderator:** Okay. And when were you diagnosed with SMA?

**Patient:** October 2012.

**Moderator:** Wow. Wait. I never didn't ask you how old you are. How how old are you?

**Patient:** I'm 43.

**Moderator:** Okay. So interesting. You were diagnosed at, like, 30 years old?

**Patient:** Yeah. Right around I think I don't know.

**Moderator:** Wow.

**Moderator:** Wow. So interesting. How did it in a in a very short story, how did the diagnosis come about? Yeah. It's interesting you're diagnosed.

**Patient:** Our Pastor's I'm sorry. Our pastor's wife is a physical therapist. She had noticed my gait and had told me I needed to see a neurologist. They had, you know, tested me for a couple things, and one of our friend's daughter actually has SMA type zero or one, and something told me to get tested for it. I had never really heard about it, didn't know anything about it. But, you know, when the testing came back negative for MS and a couple other things, I just said, hey. Test me for this.

**Moderator:** But so the upsetting part of that story is that it wasn't part of the panel of original things that they tested you for too. Like, if you hadn't asked.

**Patient:** Yes.

**Moderator:** Sorry. That brings that's just a little heartbreaking there.

**Patient:** Yeah.

**Moderator:** What a remarkable physical therapist and to know that you should get see a neurologist.

**Patient:** Mhmm.

**Moderator:** Wow.

**Patient:** Yeah. Just just watching me walk, you know, on Sundays and the little bit of of interaction we had had, she had just said, there's something going on with your gait. You need to get in, and so I did.

**Moderator:** Wow. So all the testing came back negative, and then you said to the neurologist, did the neurologist even know when you said what was the reaction when you said, actually, I wanna get tested for.

**Patient:** He was pretty Open to it, and he wasn't very well versed on it. You know, had to do some research. I was sent sent to a muscular dystrophy clinic up in, another town once I got diagnosed to kinda maybe, you know, help me learn some more about it. He was very limited in his research. You know, basically, what he found on the Internet is what he knew.

**Moderator:** Sorry. I don't know why I just giggled, but it's just intense. It's a bit like Gosh. Had you been seeing a physical therapist or have your own physical therapist before the interaction with the the pastor's wife?

**Patient:** So I had seen a doctor. I had some lower back pain, and they I guess I had what they called a limp at the time. And what they were kinda attributing it to was maybe childbirth. You know, I'd had my third son or my third child by then, and they were wanting to do a epidural to kinda, like, block some of the nerves and the pain. And, I just I didn't have it done. My husband was in the military, so, you know, we we move and and things like that. So when we got to our new duty station, kinda got settled in, you know, I was gonna try to continue care there, but she had just kinda intervened before then. I just kinda chalked it up to maybe, you know, had gained some more weight because I was always really thin before kids. You know, I was losing some I lost my ability to run. I was slowly noticing a few other symptoms, but not being knowledgeable, I just kinda chalk you know, chalked them up to, hey. I'm just fifty pounds heavier than I had ever been.

**Moderator:** Wow. 50, but it was a big change.

**Patient:** Mhmm.

**Moderator:** Wow.

**Patient:** Yeah. So I just kinda thought my weight was causing some of my issues. You Know, maybe I was too heavy for my body frame or something like that.

**Moderator:** Yeah. Wow. It's so interesting. It's so funny. Somebody attributed to the birth. Yeah. You're like, oh, let's just chalk it all up to childbirth.

**Patient:** Yeah. Yep.

**Moderator:** It's just a female problem. Yeah.

**Patient:** Right.

**Moderator:** Wow. Okay. So how did you feel when you were diagnosed? What was that? What was that? I'm sure it was, like I don't know. Yeah.

**Patient:** It was a little bit scary. You know, I didn't know much about SMA as a whole. I only knew, you know, kinda what I had seen in our friend's daughter. You know, I'll be honest. I didn't know much about it. So I had to dive in and, you know, try to research and, you know, obviously, I was scared. I have three young kids. You know, I'm married. What is my life going to look like? You know, all those things crossed my mind. You know, my biggest fear was, are my kids affected?

**Moderator:** Oh, what do you mean? Can you say more about that?

**Patient:** I was worried if my kids, you know, would have SMA, you know, just Part of just kind of, you know, processing it all.

**Moderator:** Like, was There a genetic thing that You passed that was passed down to them? I see.

**Patient:** Yep.

**Moderator:** And your friend's daughter, you said she had type zero, type one. Is she pretty severely impacted if she's Type one?

**Patient:** Yes.

**Moderator:** Yeah. And that was your one example of sma?

**Patient:** That's all I knew.

**Moderator:** Yeah. Yeah. So you were referred to a muscular dystrophy clinic. Is that what you said?

**Patient:** Yes. So they referred me up to a muscular dystrophy clinic up in a city close to us, just to kinda, I guess, maybe get their insight on it and kinda maybe see if he could give me some more, you know, information, you know, maybe learn a bit little bit more. I did take into my own hands and push to actually see a, SMA doctor.

**Moderator:** Oh, at the same place?

**Patient:** No. I pushed to go to Utah to see a specialist out there. That was the closest SMA doctor I knew.

**Moderator:** Where do you don't without telling me your actual address, what state do you live in?

**Patient:** Oh, currently, I'm in Alabama. We were in Kansas when all this was going on.

**Moderator:** Oh, okay. How did you know about the doctor in Utah?

**Patient:** I joined a few SMA pages and had heard that she or this clinic was a very, you know, well known, doctor out in Utah. And so I just kinda Pushed my insurance to go out there, because I did See, you know, I did see the neurologist up in, Kansas. Well, two of them actually. You know? And they didn't really know much. Couldn't really give me much guidance. You know? So I just decided it was my right to see somebody who could maybe inform me a little bit more.

**Moderator:** So they when you say they didn't give you much guidance, can you say a little bit more about that? This was yeah.

**Patient:** You know, I I'm being told things like live your life the best you can. I was told at one point I may, you know, hey. Your life is going to be in a wheelchair. Like, there was no if, ands, or buts about it. And and, you know, while it's not horrible, but, you you know, to be newly diagnosed, not know what's going on. I've got three young kids. You know? All these things are just spiraling. Like, what do you mean? Like, is there's nothing to help me. There's, you know basically, go home and figure Out the next wheelchair that you would like. You know? That's what it's being presented to me as And it was a lot of, well, you're walking and you're moving. We'll see you in six months. We'll see you in a year. Like, there Was not a lot of, like, hey. Try these therapies or do these things. You know? It's we'll just keep watching. Keep watching.

**Moderator:** And you said you went you were on some SMA pages. Tell me about that. You did you go, like, on Facebook or.

**Patient:** On facebook.

**Patient:** Yeah. The one lady, whose daughter we knew, she, you know, did a lot of research, kinda, I guess, found some pages. So I reached out to her. My husband and her husband were in the army together. So I just kinda found some pages on Facebook. I don't recall exactly what the names were, and just, you know, got some information from there. At the time, I was told there was really no doctors that knew a lot about, adult SMA. There was, like, one doctor in Ohio that kind of knew a little bit about adult SMA, but, I had heard there was she's more of a pediatric doctor there in Utah, and that's where they sent me. I went to a children's doctor actually in Utah, but I.

**Moderator:** And this is a neurologist?

**Patient:** I think she is a neurologist. Yeah.

**Moderator:** Okay. And how did that how did that go when you met with her?

**Patient:** Actually, I very well. She was very insightful. I spoke to a dietitian there. They did some testing. I had by then lost my ability to climb stairs, without a railing. But, you know, as they were testing me to climb the stairs, I could do it in her office. I'm like, this is not something I normally do. Like but it was it's probably one of the most informational, doctors I had had seen. She they kinda broke down, you know, SMA for me, kinda how they think I was affected, gave me a little bit more information about it, you know, better outlook. Here's some diet. You know? Like, here are some things to maybe eat and not eat. You know? Watch your calorie intake because you obviously are not as active as what a normal, you know, normal human being is.

**Moderator:** Okay. So I'm just gonna pause there, and I what I wanna do is understand where you're at now, and then maybe we'll get to fill in between now and then because I just have a little it's a fascinating beginning story that you've told me. And I just wanna so terms of now, do you…

**Patient:** I have a neurologist that I see twice a year. I'm actually in the process of swapping, but I have a neurologist I'll see basically twice a year, every six months. And that's more so because I asked to go every six months versus every year. And then just my primary care doctor.

**Moderator:** Why did you ask to go twice a year?

**Patient:** Just to maybe, you know, track my, strength and and things like that. Just kinda, I guess, to keep tabs on myself.

**Moderator:** What's your it's interesting you're switching. What's your relationship like with the current neurologist? And do you have a new neurologist picked out?

**Patient:** I do. I just have to wait a few Months to get in. I'm just swapping, more so because I've got a lot of knee issues, and I just I feel like he I don't I I like him, but I feel like he doesn't give me the best care. I feel like maybe he potentially could, you know, do more for me or try to help me more in certain areas, and I don't get that. I don't feel like I get that from him.

**Moderator:** I'm really interested in that. Can you tell me a little bit more about what you wish you would get from him and what he doesn't give you? Just help me understand, like, what what what's lacking for you. Yeah.

**Patient:** Sure. So I've had surgery on both my knees, just, you know, due to the way I walk, I hyperextend. And, you know, I went into him and I said, you know, I've I've seen orthopedic doctors for the for my knees and stuff. I said, I'm in a lot of pain. Like, I live in pain daily. And My primary care doctor, you know, she's giving me muscle relaxers and anti inflammatories and things of that nature, I said, but I don't feel like I should have to live in chronic pain daily, like and especially with my knees the way they are. And I asked him, you know, about a few medications, like, you know, or can we try this or this? And he.

**Moderator:** What what kind of medications did you say can we try?

**Patient:** Sure. So I asked him to maybe try Lyrica just because.

**Moderator:** Mhmm.

**Patient:** I had heard it's good for, you know, like, inflate inflammation and that type of thing. He doesn't want me to do gabapentin, just due to the fear of falling and things of that nature. And, he basically just told me I had to go back to my I call it my PCM, my primary care doctor, and she would need to manage all of that. Basically, anything I was asking for was outside of his scope. And I just kinda felt like maybe as a neurologist, there should be a few other things he could do for me. You know, I get It if he can't prescribe the Lyrica, but, you know, he should be able to say, hey. Maybe we could try this medication with you or do this, you know, that type of thing.

**Moderator:** To what extent do you talk yeah. Like, how much do you actually talk to your primary care doctor or PCM about the SMA, and, like, how much do they even understand about SMA? How much do you talk about it? How often does it come up?

**Patient:** It only comes up as often as I bring it up.

**Moderator:** They don't bring up the SMA, the primary care person?

**Patient:** No. I mean, no. It you know, I get the, well, your knee pain is probably due to your SMA. I'm like, okay. I get that to a certain point, but there's gotta be underlying. I do a lot of advocating for myself.

**Moderator:** That is clear. It's really impressive, actually.

**Patient:** You know?

**Moderator:** Yeah.

**Patient:** I I've gotten to a point with my PCM. I tell her I respect her as a doctor, but as somebody who lives in my body, when I ask you to go to, you know, orthopedics or wherever, I'm asking you to send me because I obviously need to go. You know? I don't go in and chase medications by any means.

**Moderator:** Do you feel like that she or the is your primary care female or male? I don't wanna.

**Patient:** She's a female.

**Moderator:** You feel like she somehow prevents you from accessing care for your SMA? Or.

**Patient:** I don't think she does. I do think sometimes, you know, we're on Tricare. I do think sometimes they try to make it a little bit harder, for the doctors. You know, and and she'll give me a referral where I ask to go. I just don't feel like there's ever the initiative of maybe let's try orthopedics or rheumatology or you know what I mean?

**Moderator:** Yeah.

**Patient:** To combat some of this.

**Moderator:** Yeah. That sounds like it's with both of those doctors.

**Moderator:** Let's dig in together and try to help you. Okay. What I wanna understand now is treatment for SMA specifically. I have written down here that at some point, you were on Evrysdi liquid. Is that correct?

**Patient:** Mhmm. It is.

**Moderator:** Okay. So tell me, when did you start the Evrysdi? Do you remember?

**Patient:** I don't remember exactly. I think it might have been in, like, November '21 August or November in that time frame of '21.

**Moderator:** When did you take it until?

**Patient:** I stopped it about a year later. I would say probably well, November '22, I believe I stopped it.

**Moderator:** Okay. So, I have so many questions. first I need to ask what led you to the Evrysdi, and I would need to ask what led you to stop Evrysdi. D. But, why don't we lead me up to when was the first time you even ever considered taking any treatment for your SMA specifically?

**Patient:** So when the SPINRAZA came out, it did cross my mind. And, honestly, one of the reasons I don't take it is I don't want the intrathecal injections in my spine. That is a huge reason why I stay away from SPINRAZA. And I personally like you know, some of the Facebook groups I'm in and stuff, yes, I've seen individuals benefit, but nothing enough for me to say I'm going to do this every four months. So that's why I don't do the Spinraza.

**Moderator:** Can I can I pause you for a second there?

**Patient:** Absolutely.

**Moderator:** What is it about like, sometimes I ask questions that seem so obvious, but I justNever wanna presume to under understand anything. But what is it about the intrathecalInjection that is a such a a downside for you? Why is that a huge, like, stay away from that one?

**Patient:** Well, I just don't wanna go every four months and have them injected into my spine, and I know there's sorry. I know there's ports that they can put in.

**Patient:** I just don't wanna have a port, you know, placed into my back or my neck or whatever. Just a personal choice more than anything.

**Moderator:** Would just like is it how much is it, like, the inconvenience of getting there? How much is it, like, you're afraid of feeling pain? Or is it, like, a fear of something going wrong or just too much invasive? You know, like, just help me break it down for.

**Patient:** Yep.

**Moderator:** Me a little bit. Yeah.

**Patient:** I think my biggest fear is something going wrong. You know, just as when you do anything, you know, any surgery, any injection, there's always that risk. And then part of it too is, you know, just getting there and possibly some of the side effects. You know, I've seen a lot of people go down with, like, the migraines and things. You know, so that does play a part in it for me, but I would say my biggest fear is something going wrong

**Moderator:** Okay. Did you and it's interestingYou said in your Facebook pages, you also didn't see a huge upside from your peers online. You didn'tSee people benefiting that much. Is that what you're saying?

**Patient:** That from what I've seen now, I'm not in every Facebook page. I'm in a, you know, limited amount. But, you know, just from some of them that I've seen, it's not enough to make me say this is worth it. It.

**Moderator:** Okay. How did you even find out about Spinraza? Do you remember how that first even crossed your.

**Patient:** I probably one of the Facebook groups I was in.

**Moderator:** Did you have the neurologist then who you still have now, who you're trying who you're leaving?

**Patient:** No.

**Moderator:** You probably were leaving living somewhere else.

**Patient:** Yes.

**Moderator:** Right? Because you move so you move pretty regularly. You don't have a consistent neurologist.

**Patient:** Yeah.

**Moderator:** Do do your neurologist ever bring up the SPINRAZA with you or that.

**Patient:** Yep.

**Moderator:** You had at the yeah.

**Patient:** Yep. So the neurologist that I, am leaving, he was actually pushing for Spinraza. He actually when I first started seeing him back in 2019, you know, he's like he he was pushing for it, I would say. And I just said I wasn't comfortable at that time. And then, so I just didn't do anything at that point in 2019 when I started seeing them.

**Moderator:** How was your SMA at that point? Like, how yeah.

**Patient:** It was I mean, I didn't have an ability to run. I lost that probably back in 2006 after I had my first daughter. I would say I was pretty stable, pretty, I don't know, well off.

**Moderator:** Okay.

**Patient:** So back in 2019, I would say I was still pretty good. You know, I had some knee issues with my right knee, but, otherwise, I was I was pretty.

**Moderator:** And were you able to, like, you by that point, you were not walking upstairs. Is that what you're saying?

**Patient:** Good. I would use railing. I would pull myself.

**Moderator:** Okay. Really?

**Patient:** Yeah. So anytime I do, like, any type of stairs even today, I have to, like, essentially have a rail and, like, pull myself up. It was easier back in 2019 than it is today.

**Moderator:** But are you, I never even I forgot to ask you. Like, what? I I know I'm interrupting, and I apologize for being a little.

**Patient:** You're fine.

**Moderator:** All over the place. But how does your SMA affect you today? We'll just do a little interruption while we get and we'll go back to the.

**Patient:** Sure. So I cannot run. I do not I cannot squat. Well, I can squat down. I can't get back up, essentially, without, like, using my arms. I use my arms to get up from any seated position. Obviously, my gait's affected since, you know, it's been affected for a long time, like curbs and things of that nature. I have to have somebody, like, I guess, pull me up, or I have to hold on to somebody to get a a curb.

**Moderator:** Do you use any kind of mobility assistant, like a cane or.

**Patient:** Nope.

**Moderator:** Don't you don't use a wheelchair? I know you mentioned the wheelchair before. No.

**Patient:** Mhmm.

**Moderator:** Okay.

**Patient:** Nope. I don't use any type of assistance,

**Moderator:** Okay.

**Patient:** I guess, unless I'm going up or downstairs.

**Moderator:** Okay. And you're able to let lift things and I mean, I see your arms moving, but yeah. Does it affect your upper body at all? Yeah.

**Patient:** A little bit. I mean, my upper body, I'm actually fairly well off.

**Moderator:** Yeah.

**Patient:** I did notice, like, we replaced a gate, our fencing in between our houses. You know, trying to lift a 50 pound bag of concrete, it's out of the question. You know, things like that. I do have limitations on what I could list, but yeah.

**Moderator:** But you're pretty yeah. You're remarkably, though, like yeah. You have a lot of physical capabilities, though, still. Like.

**Patient:** Yes.

**Moderator:** Yeah.

**Patient:** Yeah.

**Moderator:** Yes. That is remarkable. Okay. Sorry to interrupt.

**Moderator:** Your SMA ..do you feel like today your SMA is stable or slowly progressing or more rapidly progressing? Or what do you what'd you say?

**Patient:** I'd say probably slowly progressing. I see little things. You know, like, I feel like I maybe fall a little bit more often, and I go in spurts almost. Like, I might fall two or three times and be good for a couple months. You know, noticing that some things I really can't lift that I used to be able to.

**Moderator:** 50 pounds of concrete.

**Patient:** Yeah. Yeah.

**Moderator:** Look. I can and okay. Okay. So let's go back to your this is a problem of too many things to ask you. Okay. We'reBack to your timeline. So 02/2019, your neurologist kind of put was pushing this SPINRAZA, and you're like, look. I'm just not comfortable. It sounds like you're describing the potential what you understood to be the upsides, not outweighing what you felt were the downsides, if that seems okay.

**Patient:** Yes.

**Moderator:** Okay. And then what so then two years passed, what led to going on the Evrysdi? Talk to me about all the little details of how that ended up happening.

**Patient:** I probably heard about it through, you know, another SMA page or the current one I was on or whatever. And the convenience, honestly, is what attracted me to the Evrysdi. You know? Let's hold out hope that this would be, you know, a great medication that would potentially, you know, either keep me where I was at or maybe show some improvements. And So that's why I chose Evrysdi.

**Moderator:** Mhmm. Did you bring it up to your neurologist or did the neurologist bring it up to you?

**Patient:** I brought it up to him. I came in with my papers printed so he could sign them.

**Moderator:** Isn't that fascinating?

**Patient:** Yep.

**Moderator:** And.

**Patient:** He was on board.

**Patient:** Oh, yeah. Yeah. He was always on board for me to be on some type of treatment.

**Moderator:** Mhmm.

**Patient:** And, you know, when I would go in for my every six months checks, you know, he'd be like, do you wanna go on the Spinraza now? Nope. Nope. You know? It was me. A 100% me that stopped that. It was not him at all.

**Moderator:** But it's interesting. I'm I'm not good at remembering when Evrysdi came on the market. But my sense is that it was on for at least a year by the time you got on it, that it was available for at least a year, I think.

**Patient:** I think so. Yeah. And maybe I went on it a little bit earlier, but this is kinda like what I'm trying to remember.

**Moderator:** Right. It doesn't matter. It's all but yeah.

**Patient:** Take a little while in order, you know, to get it processed. I had some denials through insurance, ended up going on a foundation. You know, it wasn't a quick in and out process for me.

**Moderator:** What was the what do you mean a foundation? Can you talk so you yeah. Like, you got denied a couple times with insurance. Is that what.

**Patient:** Mhmm.

**Moderator:** You're saying?

**Patient:** Yeah. So our insurance denied me. We appealed it

**Patient:** I feel like it was like a generic denial, something to do with my age, which at that time made no sense to me. And so, you know, we submitted all my, I guess, my background so they could see why I needed it, and we were I was still denied. So at that point, the I think it was the Genentech Foundation, they picked me up or provided the medication to me through their foundation at no cost to me.

**Moderator:** Wow. How did you find out about that? Or how how did that come about?

**Patient:** So when I applied for Evrysdi, I was assigned a I think they're called pals. Oh, it was named in wrong. A representative from Genentech. Let's just put it that way. You know, they reach out to you like, hey. We're here. Walk through the steps with you. Any questions? You know? Basically, just just your friend from Genentech to kinda help you through, you know, which is sweet. I like it.

**Moderator:** How how was how was having that that pal or that person?

**Patient:** I enjoyed it, actually. She checked in on me quite often and, you know, just tried to encourage me to work through it. You know, obviously, couldn't tell me a lot of things, but was baffled that I was denied because she had several others on my, you know, type of insurance who were getting approved. And, you know, still to this day, kinda baffled why I was denied. But, anyway, so they she told me about the foundation. You had to apply, and there was, like, some, income limitations and guidelines and stuff like that. So, yeah, that's how I got on it.

**Moderator:** Okay. And so you stayed on it for a year. How did that tell me all the in the ups and downs, ins and outs, or what was it like for you to be on.

**Patient:** You're.

**Patient:** I started out on it. I can't remember. I think it was five point five mls was the full dose. Did okay for a little while, and then I started noticing a few side effects. Like, I was having a left foot drop. I had noticed, like, a little bit where.

**Moderator:** What.

**Patient:** My,

**Moderator:** Does that what does that mean exactly?

**Patient:** Like, my left foot would almost, like, slam more when I walk.

**Moderator:** Okay.

**Patient:** I call it a foot drop. Like, I was having more trouble, I guess, controlling my left.

**Moderator:** Okay.

**Patient:** Foot. And I drive independently, and I was getting in my car one day and had noticed I was picking up my left leg and, like, slinging it in my car. Like, I had almost lost some, I guess, function of my left leg or weakness. I was becoming weaker. So I came home and thought about it and took myself off of it for a little while. And just to kinda see, like, hey. Did this improve? Did this not improve?

**Moderator:** Just decided on your own to do, like, kind of an experiment?

**Moderator:** You're right. It did make me laugh.

**Patient:** I did. So I was like, I think I went off of it for about two weeks and just to kinda see what I was feeling. Was it in my head? Was it not in my head? You know what I mean? And I kinda felt like I was feeling better. Didn't really notice the foot drop or the leg weakness. And then I was like, well, maybe it was a fluke. You know?

**Moderator:** Okay.

**Patient:** So then I went back on it, and I was starting to notice some weakness again. So then I reduced my amount I was taking a little bit because it's just what I do. You know? Before Into my neurologist and I'm like, hey. I wanna take half a dose, I wanted to try it myself just to kinda see. And, so I reduced it. I think I started taking about three, three and a half ml just to kinda see. And I I did notice that the foot drop or the leg weakness really wasn't there, But I started to notice, like, some personal side effects, like, I guess, intimacy side effects that I wasn't liking. And,

**Moderator:** And do you think they were would you feel comfortable sharing them with me? I know we're being recorded, but.

**Patient:** You're fine. And I don't know if it was exactly the medication, because I, you know, I have had a hysterectomy in life, but I just I started losing any, like, desire for sexual activity, which really was Not meSo, you know, I decided to go back off the medication again I kinda felt like they came back. And I don't know. It could have been coincidence, could have been whatever. I just have mentally tied it to that, and I don't find the weakness. Like, you know, I didn't have the left leg weakness and the foot foot weakness while I was off the medication. So I decided to go off of it. Well, back up a little bit. Sorry. I ended up having a procedure done. I had some liposuction done in November '22, I think. '20 and, I had to go off of the medication just because they weren't quite sure, you know, if there's any side effects saved or not. So I went off of it, and I just kinda made the decision.

**Patient:** You know? And even still today, you know, I don't have some of those side effects I was having while on the medication, so I do feel like it was really the medication.

**Moderator:** Yeah. It's interesting. Yeah. The libido thing is is really interesting. That plus the foot drag and that yeah. Like, you seem to feeling better seem to be, like, negative correlated for you with being on medication. Like, when you're On the medication, you felt worse. Yeah. Did you ever talk to your doctor about getting off the medication? It sounds like it was a very self managed I mean, on some level, your SMA whole experience sounds self managed.

**Patient:** So I did talk to my neurologist about going off of it. He did not support me. He's like, you know, you need to when I say didn't support me, he highly encouraged me to stay on a form of medication. You know, he's like, there are studies out there. There is, you know, statistics behind these medications showing they're beneficial. And I said, well, with all due respect, I'm staying off of it. We can talk again in six months. And, you know, we had talked a little bit here and there, and I I ultimately was going to go back on Evrysdi at about a half dose just to give it another try. I thought I'm older, maybe life changed, maybe my body's changed. I don't know. I'll give it another go. You know what I mean? Again, I I did run into the roadblock of insurance. Insurance did deny me again.

**Moderator:** Wait. Wait. Hold hold on. When did you decide to go on back on half dose? When were You were gonna do that? Yeah.

**Patient:** So we're in October. I would say it was probably in June of '25. I was gonna go back on it.

**Moderator:** Okay. Let me pause you for a second. Tell me about that because that's a pretty that's like, you had made this decision to, like, not go back on after the liposuction of twenty two. And then two and a half years later, you're like, I think I'm gonna try it again. Like, talk to me about what was up with that.

**Patient:** Mainly just I I've seen some decline in my, mobility and, you know, my doctor keeps asking me to go back on, you know, keeps telling me all the reasons to go back on, and I thought, okay. Maybe I'll actually listen.

**Moderator:** Can I pause you there for a second?

**Patient:** Yeah.

**Moderator:** What do you think I'd love to get some detail there on, like, what did he say that actually motivated you to consider going back on? Like, what were what were the pros and cons going through your mind in June '25?

**Patient:** He just really you know, he tells me and he's told me pretty much from the beginning, you know, there is studies and statistics that show, you know, it is beneficial. Patients are seeing either, you know, an improvement or a whole you know, a steady hold, you know, not declining or, get or improving.

**Patient:** And, you know, he keeps telling me, he's like, there's a reason for this medication. There's a reason why we're pushing. You know, of course, he always threw SPINRAZA back out there to me, but I kinda said, that's off the table. You know? If I go back on anything, I'll go back on Evrysdi. And so that's just kinda where where I was.

**Moderator:** How did youFeel how did you feel about his sort of pushing, like, continually bringing it up and saying there's a reason for this medication or these studies.

**Patient:** I I can't say I was opposed to it. You know, I'm not shy. So I've had I've had a couple conversations with him that sorry. You know, I respect him. I know he's a very well trained doctor. He's excellent in his field, but at some point, you have to respect me and my choices.

**Moderator:** Yeah.

**Patient:** You know? I'm not mad that he asked me, but, you know, I've stood firm a couple times. Like, I've told you this isn't what I wanna do. I'll see you again in six months. Like, that's just where im at.

**Moderator:** Ultimately tipped the balance for you from holding holding off to, like, okay. I think I'm gonna try. What was it?

**Patient:** I think just just to see, maybe because I was declining a little bit, I felt like that.

**Moderator:** What were the specific things that you felt like were declining?

**Patient:** I I think my stamina has gone down a little bit in some areas. And, obviously, my hyperextension, you know, bothers me with my knees a lot, and I thought, oh, maybe if I can at least sit idle where I'm at, you know, I'd rather sit idle. If I can't improve, let's not get any worse. You know? I'm 43. I still have a lot of life left.

**Patient:** And I and, you know, I know I can always come back off of it if I get the same side effects. I know that this isn't permanent, I guess. Like, I know that I do have the option of coming back off.

**Moderator:** Yeah. Did is this something you talked to anybody about? The like, should I go on the medication? Should I not go on the medication? Besides your neurologist, anyone else you would talk to about this decision?

**Patient:** I mean, I've chatted with my best friend about it. You know what I mean? Like, just in casual conversation, but no other medical professionals.

**Moderator:** What about, like, anybody else? Like, is it something you talk to people about on, like, your SMA pages or your primary care physician or your husband or blah blah blah or, you know?

**Patient:** I mean, I've thrown it out to my husband, and he supports whatever choice I make. Ultimately, you know, it's my body. I'm the one that lives with it. You know, I I do read on some of the SMA pages, you know, when there's people having side effects just like I was. There are people coming off of it just like I chose to. There are people having great you know, either staying steady or, you know, gaining some abilities. So I feel like it's very individualized, maybe.

**Moderator:** Yeah. Yeah.

**Patient:** You know, it wasn't something I went into blindly. I didn't wake up on a Monday and be like, well, I'm just gonna go off of this. You know what I mean? It's something I felt like I had to do to kind of decide if this is really what it was. You know? Is this the medication, or is this the SMA?

**Moderator:** You mean, in '20 in in past June, you were like, look. I need to really make sure that.

**Patient:** Well, yeah. And I just my whole whole experience through. You know what I mean? Like, let's go back on the medication this past June, and let's just see if I can hold steady. Let's see if the foot drop Comes back. You know what I mean?

**Moderator:** Okay.

**Patient:** I kinda look at it at big picture. You know? And I do. I I've talked to my best friend. You know? And, of course, she's like, you should go on it if it's a medication that'll help you. But I've told her, I said, you know, here's where my holdup is. And that's kinda where I've come to the conclusion of why not try it again? It's not permanent forever. You know what I mean? That's the kind of the way I look at it. If I'm seeing a hold steady or an improvement, okay, I can stay on it. If I start declining or, you know, seeing that maybe I'm having a foot drop, can we reduce the amount I take? Do I just go back off of it? You know?

**Moderator:** Okay. Alright. So June 2025, you decide to go back on What what happens?

**Patient:** So my neurologist submits the paperwork to my insurance, and I'm denied. And we did, of course, you know, we did the, the appeal and just denied again, more so just age. And so I do have the option to go back through the foundation, and I just never really applied to go back through them. I guess by that time, I knew that I was potentially going to leave his office. So why start going through the foundation if I know I'm probably going to leave and go to another neurologist? So I just kinda sit idle, and I'm waiting. I go in December to my new neurologist and just wanna have that conversation with him and just, you know, see where he's at, kinda see where his knowledge is and his take on.

**Moderator:** When did you decide to switch neurologists? When when did that happen?

**Patient:** I think probably in July, August, you know, I was having a lot of issues with my knees. And I think probably what ultimately sealed the deal for me is when I went in to see him in, you know, the June time frame, and he basically told me my PCM or my primary care is the one who basically has to control, you know, the pain and stuff like that. I thought, I've been coming to you for so long. No. Like, I need somebody who's actually going to help a little bit more.

**Moderator:** Yeah. Yeah. It's interesting about I'm just interested in staying here for a second about these this you that you had made a decision after these two and a half years or whatever, if I'm getting the time right, to finally go back on Everest. Do you have these two roadblocks of being denied twice? It's hard for me not to express my frustration about that, but whatever. Yeah. How did that make you feel? I must just say my feelings. How did that make you feel when you got that second denial because of your so called age?

**Patient:** I mean, it's irritating, but I'm almost not surprised. Do you know what I mean? It's like I feel like everything's kind of been a fight. I had to fight to go to see the SMA doctor out in Utah. You know? I had to fight insurance for that. I've you know, I have to fight to see doctors who I wanna see. You know what I mean? Like, I've seen local orthopedic doctors here for some of my knee issues. Wasn't getting what I thought was quality care, so I had to fight to go to, you know, Vanderbilt. And it's just like a constant fight. And I guess so it's par for the course. I knew it was gonna happen.

**Moderator:** When you thought about the foundation as a potential next step, like, how did that make you feel? The like, what would it what would it would have been what would it have entailed for you to have worked with the the Everest d Foundation, the Genentech Foundation to get the Everest d through them? Like yeah. I guess I'm asking two questions. Like, literally, what did you have to do, and how did that make you feel, the prospect of doing that?

**Patient:** So I just had to apply through them, and I had to tell them, like, what our yearly income is. And they do, like, a checkup every so often. Like, hey. Are is your income still here? I'm grateful that they offer it. You know what I mean? I wouldn't say, like, you've gotta jump through any hoops or anything. Of course, there's a little bit of paperwork, obviously. And they do have it set. Like, if you make over a certain amount, then it's, like, $30 a month or whatever. Don't quote my prices, but, you know, it's not just a no. Okay. So your, you know, your income bracket is from here to here. Well, then you paid this portion of it or whatever. So, you know, I'm grateful they do have foundations like that that can help people.

**Moderator:** How did the prospect how did you feel when you were because it sounds like you were at this fork. Right? Like, that you could have either reached out to the foundation or or decide to just, like, I'm just gonna put it on hold, for my next doc to talk about with my next doctor. I guess I'm trying to understand the heck why you decide like, just to understand a little bit more about why you didn't just continue on. Like, was there some sort of sense of, like, I don't know, like, didn't wanna deal with it or, like, this is a pain in my butt or, it wasn't worth it or I don't know. I'm just trying to understand a little bit more.

**Patient:** I didn't apply for the foundation this time just because I knew I was gonna switch neurologists, and I didn't wanna go on it, you know, if Evrysdi or apply through the foundation. And then here comes December. I'm leaving that doctor to have to do it all over again. I've Been off of it for this long. What's a couple more months? You know?

**Moderator:** Okay.

**Patient:** Like, that's honestly what my mindset was when I was denied. What you know? Why apply to the foundation if I know I'm not staying there? I knew if my insurance picked it up, I could stay consistently. You know what I mean? It's just a change of doctor. Doctor.

**Moderator:** About the program. Is there some way in which the foundation coverage is tied to a specific doctor? So if you had switched doctors, you would have to reinstate the coverage or or some or, you know, or reinstate something?

**Patient:** Honestly, I don't know. I guess inMy mind, that was my thought process. Like, I didn’t do the research. You know, the the first time I was on it, I knew I was staying with my neurologist. This time, I was like, why am I even gonna apply if there's gonna be more paperwork in three months? Like, let's just Do this. You know?

**Moderator:** Right. Right. Right. Right. Yeah. So how do you thank you for putting up with my thousands of questions too.

**Patient:** Oh, no. You're good.

**Moderator:** How are you feeling about the pro like, how are you feeling about you and treatment moving forward? Just for in general about you and SMA treatment broadly.

**Patient:** I'm hopeful. I mean, you know, I'm hoping that there's more advances. You know, I do see the the younger crowd, the ones that do the Zolgensma, you know, how well.

**Moderator:** Mhmm.

**Patient:** They've done on it. You know, I'm hoping us type us old folks, you know, we get some of that too. I'm open. I'm open to treatment, but, you know, for, like, intrathecal and stuff like that, it would have to be I'd have to see a proven hardcore record for me to say I'm jumping on that treatment. You.

**Moderator:** Yeah.

**Patient:** Know what I mean? And and I know there's no clear cut for every you know, just because this person on SMA did well doesn't mean I'm going to. I I get it. It's very individualized just like SMA is. But I I guess.

**Moderator:** Yeah.

**Patient:** I just don't see enough people saying, I've gained for me to say this is the path I'm going to take. So that's probably why right now, why I'm looking at the Evrysdi.

**Moderator:** Yeah. Are you aware of any besides Zolgensma, are you aware of any other SMA treatments coming down the pipeline that might be?

**Patient:** I feel like I am, but I can't remember right now. Like, I feel like I've seen one that they opened up, and maybe it was the Zolgensma that they've opened up into, like, an older not under two. You know what I mean? They're, like, up to 10 or something like that. I think that's what I'm thinking of.

**Moderator:** Yeah. Zolgensma is being, tested on two to eight two to less than 18 years old, so.

**Moderator:** Have you heard of anything else coming down?

**Patient:** I there's a guy in one of my groups. I know he was on a trial. I don't remember what it was called, but that's all I really know right now.

**Moderator:** Yeah. I guess there's, like, a higher dose of SPINRAZA that's being tested.

**Patient:** Oh, yes.

**Patient:** I I heard that one. I know the tablets are out for evrysdi.

**Moderator:** Right. Yeah. There's a higher dose of SPINRAZA, the tablets, and Then there's this a come a a medication you would take in combination with either EvrySD or Spinraza called an anti myostatin either through that's being tested in Scholar Rock or Roche. It, like, targets muscle growth specifically. You just but you'd have to take it in combination with, the. Get rid of that one.

**Patient:** I think I have is that the peptide one? I I wanna say someone posted where it's like a peptide. I was trying to see if I could tell you really quick.

**Moderator:** Someone will tell me. Isn't it great that I'm looking it up as we someone's writing it while I'm googling it.

**Moderator:** Yeah. It's an anti myostatin SMU peptide.

**Patient:** Okay. So I've heard a little bit. One of the ladies posted in the group.Something to do with the peptide. It had been tested, if I recall correctly, in a I think it was a gentleman who was paralyzed, and he has the ability to walk now due to this therapy. It's The article she had posted.

**Moderator:** Yeah. Yeah.

**Patient:** Yeah.

**Moderator:** I don't know about that specific ability, but there is, like, this Scholar Rock study and they're testing these anti myostatin. Ugh. This I'm so bad with these chemical names.

**Patient:** Oh, you're good.

**Moderator:** Oh, no. You don't wanna hear me try to say this. Pitagramab. That's totally wrong. But I don't know where the peptide situation come. I'm not a chemist or whatever. But,

**Patient:** Yeah.

**Moderator:** What are your thoughts about, like, those I mean, well, first, let's start with a higher dose of Spinraza. Any thoughts about that? And you or.

**Patient:** If it works for, you know, others, I'm all for it. You know? Right now, it's not on my radar.

**Moderator:** Yeah. Any thoughts about evrysalis in a tablet versus the liquid?

**Patient:** I think it's awesome. It sounds like you can travel a little bit easier with it and, you know, maybe ease of it didn't taste the best in the liquid form, so maybe the tablet's good. I don't know. You know?

**Moderator:** Does that make any difference to you, the fact that it's available in a tablet in your interest in taking Everest? Do you the fact that it's in tablet now and not just liquid? Did that matter at all to you?

**Patient:** No. I'm okay either way. I mean,

**Moderator:** Yeah. Yeah.

**Patient:** I guess, you know, if I traveled a lot or something like that, maybe the tablet would be more convenient, but I just took my little cooler.

**Moderator:** Okay. So are you I mean, just broadly, to what extent do you feel connected to the SMA community, would you say?

**Patient:** I wouldn't say I'm I'm probably about a 30. I don't I don't really get super involved in, like, the little community walkathons or rollathons and stuff like that. I I read on, you know, some of the SMA groups and stuff. I don't have any close friends that have it. You know? Honestly, that's where I get most of my information. I either, you know, read on the estimate groups on Facebook, might pick up an article here and there, that type of thing.

**Moderator:** What do you what do you say article? Like, where are you getting those articles?

**Patient:** Sometimes people share them on, like, the SMA groups I'm in, or I, you know, I can was it SMA? Trying to think of the page now. Like, there's an SMA page. It's probably just more, like, for the yearly conventions and stuff they do. You know, I just read articles that people.

**Moderator:** You don't.Get any, like, website or, like, there's a Cure SMA and ..

**Patient:** CureSMA. That's the one. Yes.

**Patient:** On there sometimes. Yeah.

**Moderator:** Okay. Would you say there's any you know, some people I meet are really involved in the SME community and some people are not, and then there are people in between. Anything you can tell me to hunt help me understand why you feel like you're only a 30? I'm assuming that's out of a 100. But, like, why.

**Patient:** Yeah.

**Moderator:** Yeah. Like, what is do do you have any ambivalence about being further part of the SMA community, or do you not really identify with the SMA community, or does it make you feel a certain way? Or I don't know.

**Patient:** I guess it's just a choice. Like, I don't, you know, exclude myself by any means. You know, I'm part of this community with them. I guess, you know, most of it's, like, two hours about south of me, where.

**Moderator:** People are meeting in person, you mean?

**Patient:** Yeah. In my local community, I don't really know of anybody. You know, in my state, there's a couple ladies I talk to, you know, via Facebook in my state, but I've never met them.

**Moderator:** Do you wish you were more involved with the SMA community, or are you sort of just good with the amount that you have now?

**Patient:** Yeah. I mean, if time allowed, I would be more involved, and maybe if there is, you know, things closer. I just I can't drive two hours one way.

**Moderator:** Right. Totally. Yeah. Yeah. Yeah. If you were to think about well well, first, you get a meet with this how did you find your new neurologist?

**Patient:** I I googled just local neurologist in the area. There were two that I was interested in, and I'm on a mom to mom group. And this neurologist that I'm going to has a lot of patients who respect him. Now they're not SMA patients. They're just, you know, neurologist patients. They go there for whatever needs they have, but, I figured it's worth a try. You know, there's nobody in my area that specifically is, you know, SMA, like, specific or whatever.

**Moderator:** What kind of, do you live in a rural area, suburban area, urban area?

**Patient:** I guess it's kind of rural. We're not far from a a big city. We're kinda outskirts, I guess.

**Moderator:** Okay.

**Patient:** About thirty minutes.

**Moderator:** Okay. What imagine that you at your next doctor's appointment at the neurologist, what do you think you might say to the doctor about treatment and possible treatment? How do you think you might do you think you'll be the one my sense is do you think you'll be the one to bring it up? Almost I'm, like, ridiculous asking that question, like, duh.

**Patient:** Yeah. No. You're good. Yeah. And that's part of what I wanna talk to is, you know, tell me what you know about both of them and tell me your reasonings why you're gonna sway towards one or the other. Maybe he's got the magic word to say, go on, Spinraza. This is where, you know, I believe it's gonna take you, or, hey. Stay with Evrysdi. Here's my reasonings why. You know, that type of thing. I wanna know how involved he can help me get also. You know what I mean? Like, if a clinical trial comes around, you know, is how do I look into the you know? I know I can apply to some of those on certain sites, but, like, what what do you know? What other avenues do you have? Who else do you think I need to see? I just wanna see what his outtake is.

**Moderator:** What yeah. Ultimately, what do you think is gonna be most influential in your decision to start or not start treatment? Like, what do you think will be the biggest factor for you?

**Patient:** I mean, if he's got great information and maybe some success stories for, you know, either one, sharing those with me may sway me. Right now, I do know that I'm gonna go in, and I'm probably gonna ask to go back on Evrysdi. You know? I wanna go in at half strength to try it to kinda even if I have to taper up. That's my goal right now. If I was sitting in his office right now, I would say, I'd like to go back on to Evrysdi. This is where I wanna start, and this is why I wanna start here.

**Moderator:** If the doctor says I don't want you to start on a half a dose, would you just do it anyways without.

**Patient:** Probably.

**Moderator:** Yeah.

**Patient:** I know that.

**Moderator:** No.

**Patient:** Shocks you, doesn't it?

**Moderator:** It it doesn't. It just.

**Patient:** We know.

**Moderator:** Cracks me up. It's not shocking based on what you said before. It's hysterical.

**Patient:** No.

**Moderator:** No.

**Patient:** I know.

**Moderator:** I I think it's funny. Is there anything that you, like, that you could wish for, like, to help make the path to treatment better for you? Like, what do you what would make it what would make you feel more confident or make it just feel better about potentially restarting a treatment? Like, what what would help you right now? Like, imagine I think you're and that isn't till December. Right? That,

**Patient:** Yeah.

**Moderator:** Like, if you could, like, wave a magic wand, what would you say, gosh. I wish the doctor would do this or the manufacturer would do this or the world would be like this or the blah blah blah,

**Patient:** For the current treatment that's out or just in general?

**Moderator:** Whatever. For the current say you were gonna go back on a RISD, like, what would make what would make that easier or make you feel more comfortable or yeah.

**Patient:** Just not finding any decline.

**Moderator:** Yeah.

**Patient:** You know, I did have it before. And and maybe this is where I'm pivoting in my life to say, giving it another try. If I do see the decline, maybe I do I do try the Spinraza at that time. You know? Maybe that's what I need. You know? I'm not there yet, but maybe this chance, you know, help me decide. Hey. You know what? I'm staying where I'm at. I'm not seeing any decline. This is where I need to be. Hey. You know what? No. I am declining. This is not where you need to be. Maybe you do need to try a different therapy.

**Moderator:** Yeah. Is there anything that, SMA medication manufacturer could do to support you in the possible transition back to treatment?

**Patient:** I don't know. I think maybe some of the you know, doing a little bit more for the older crowd. You know what I mean? I get it. The young kids are young and, you know, we wanna save them all, but I almost feel like some of us older, you know, type three, type fours, we're just kinda, like, left out there. Like, throw some more type threes, type fours into the mix.

**Moderator:** So it's so interesting because you're not the first person to say that to me because, what would that actually look like? What would, you know, what what would it yeah. Be more specific. Tell me about this more. Like, just feel yeah.

**Patient:** I think it is amazing, these two year olds, eight year olds, 10 year olds, or whatever, you know, how well they're doing, how, you know, wonderful the therapies are for them. Show me what 43 year old out there has had the same outcome, you know, or 63 year old or whatever. Maybe try some of the older crowd to actually see what it does. I get it. I get, you know, you have to build up. You have to try things. You know? I get it's all learning, but there's a lot of us out there that would be willing to be part of it to open up to just more than, you know, the younger crowd. I callThem the younger crowd, but you know what I mean? Those under 18 or, you know, 18 and under. Show some of us older folks who are type threes and fours. Yes. We're very blessed to be where we are in life, but we still matter.

**Moderator:** Do you feel sometimes that, like, it's there's not..It's not being made clear that the older SMA patients still matter to these manufacturers. Yeah.

**Patient:** Mhmm. Yeah. And I get it. I you know? Yes. I understand the you know, zeros, ones, twos are a little bit more critical than we are. I do understand that concept, but I also feel like we don't matter as much.

**Moderator:** Yeah. Yeah. I've definitely heard that. Other people saying that too. Other adults, obviously.

**Patient:** No.

**Moderator:** I'm sorry. That must be a crappy feeling. One last question I have. You know, I asked you about sort of feeling connected to the SMA community and, you know, you're look linked to you're LinkedIn. You're connected to these Facebook pages and you're clearly getting information from that source these sources. Would you ever want are there any other ways you wish you were connected to s to the SMA community? Like, do you ever wish that you were, like, talking to a fellow peer about SMA? You've talked about not having friends for SMA. Would you ever wish you were connecting with a peer, you know, online or over video or on the phone or on email? I don't even know exactly how the connection would happen.

**Patient:** I think that opportunity is there. You know, I've private messaged, you know, on Facebook a couple of the ladies on the groups and stuff. Like, just couple questions and stuff like that.

**Moderator:** Yeah.

**Patient:** So I do think that avenue is there. I just I guess I don't necessarily pursue it. I I know.

**Moderator:** Do you wish someone would proactively reach out to you?

**Patient:** No. Not really. I I think I'm content in that area. I have enough support, you know, through my husband, through friends who are not SMA.

**Moderator:** That's nice.

**Patient:** You know what I mean? They may not exactly understand a 100% what I'm going through, but I know that they are there to support me. I do know that, you know, there's a couple SMA women's groups. You know? Some of us all go down there and say, hey. You know? This this or that, and we all kinda chime in. So there is a a little bit of a sisterhood there. So I don't feel like I'm outcasted by any means. And I do know if I wanted more, I could have more.

**Moderator:** Great. Thank you so, so much for participating, for putting up with my endless nosy questions And just being willing to share so much. It really was enormously helpful. So. And I know this is a long interview, so thank you for persisting through all of it. And, like, hats off to you being an amazing health advocate. Like, some I I oftentimes wonder what are the factors that lead people to be able to be amazing advocates because a lot of people aren't. And, it's really moving to hear that you are. So.

**Patient:** Well, thank you.

**Moderator:** Yeah. I wish you all the best.

**Patient:** Goodbye.