**qual test**

*Oct 1, 2025 | 12:00 PM | R02 Transcript*

Date: October 1, 2025

Time: 12:00pm

**Moderator:** Samantha, my name is Nancy. It's so nice to meet you.

**Respondent:** Nice to meet you.

**Moderator:** How are you doing today?

**Respondent:** Good.

**Moderator:** Good. Before we begin, I just want to give you a quick introduction. I really appreciate you joining today, and we're going to be talking all about SMA and SMA treatment in particular. Everything you say today is completely confidential. I don't even know your last name, so let's just keep it that way. Please try not to tell me the name of any doctors involved in the SMA treatment. 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 mention 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 think you agreed to give seventy-five minutes of your time. Is that correct?

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

**Moderator:** So even though that seems like a really long time, every once in a while, I still need to interrupt folks just to hustle things along because I do have a ton of questions. Are you okay with all that?

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

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

**Respondent:** I have SMA.

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

**Respondent:** Sure. I live with my children and my husband, and we have two dogs. I work part-time for a local school, and I am enrolled in school to earn my bachelor's. I do all the other daily things in between.

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

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

**Moderator:** Wow. You're full on. I have one 16-year-old and two 14-year-olds, so just behind you. And what do you do when you work part-time for the local school district?

**Respondent:** I work at the front desk. When the kids come in late or need to check out, I 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. What are you majoring in? Sorry, these are just nosy questions. They're not crucial, but it helps me get to know you a little bit.

**Respondent:** You're good. I've got my associate's in medical coding and billing, in medical office admin, so I thought it'd be fun to get my bachelor's in human resource management.

**Moderator:** I mean, there's a lot of detail in both. Right? A lot of systems stuff. Even HR is a lot of systems too. Right?

**Respondent:** Yeah.

**Moderator:** So when your type three SMA. Is that right?

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

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

**Respondent:** October 2012.

**Moderator:** Wow. How old are you?

**Respondent:** I'm 43.

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

**Respondent:** Yeah. Right around there.

**Moderator:** Wow. How did the diagnosis come about?

**Respondent:** Our pastor's wife is a physical therapist. She noticed my gait and told me I needed to see a neurologist. They tested me for a couple of things, and one of our friend's daughters 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 when the testing came back negative for MS and a couple of other things, I just said, hey, test me for this.

**Moderator:** 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...

**Respondent:** Yes.

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

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

**Moderator:** 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 want to get tested for SMA?

**Respondent:** He was pretty open to it, but he wasn't very well-versed on it. He had to do some research. I was sent to a muscular dystrophy clinic in another town once I got diagnosed to help me learn some more about it. He was very limited in his research. 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.

**Respondent:** Yeah.

**Moderator:** Had you been seeing a physical therapist or had your own physical therapist before the interaction with the pastor's wife?

**Respondent:** I had seen a doctor for some lower back pain, and they attributed it to maybe childbirth. I had my third child by then, and they wanted to do an epidural to block some of the nerves and the pain. I didn't have it done. My husband was in the military, so we moved. When we got to our new duty station, I was going to try to continue care there, but she intervened before then. I just chalked it up to maybe gaining some weight because I was always really thin before kids. I lost my ability to run and noticed a few other symptoms, but not being knowledgeable, I just chalked them up to being fifty pounds heavier than I had ever been.

**Moderator:** Wow. 50 pounds is a big change.

**Respondent:** Yeah. So I thought my weight was causing some of my issues. Maybe I was too heavy for my body frame.

**Moderator:** It's so interesting. Somebody attributed it to childbirth.

**Respondent:** Yeah.

**Moderator:** How did you feel when you were diagnosed?

**Respondent:** It was a little bit scary. I didn't know much about SMA as a whole. I only knew what I had seen in our friend's daughter. I had to dive in and try to research. Obviously, I was scared. I have three young kids. I'm married. What is my life going to look like? My biggest fear was, are my kids affected?

**Moderator:** What do you mean? Can you say more about that?

**Respondent:** I was worried if my kids would have SMA.

**Moderator:** Was there a genetic thing that you passed down to them?

**Respondent:** Yep.

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

**Respondent:** Yes.

**Moderator:** And that was your one example of SMA?

**Respondent:** Yeah.

**Moderator:** So you were referred to a muscular dystrophy clinic?

**Respondent:** Yes. They referred me to a muscular dystrophy clinic in a city close to us to get their insight and maybe learn a little bit more. I took it into my own hands and pushed to see an SMA doctor.

**Moderator:** At the same place?

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

**Moderator:** Without telling me your actual address, what state do you live in?

**Respondent:** Currently, I'm in Alabama. We were in Kansas when all this was going on.

**Moderator:** How did you know about the doctor in Utah?

**Respondent:** I joined a few SMA pages and heard that this clinic was well-known. I pushed my insurance to go out there because I saw two neurologists in Kansas, and they didn't really know much. I decided it was my right to see somebody who could inform me a little bit more.

**Moderator:** When you say they didn't give you much guidance, can you say a little bit more about that?

**Respondent:** I was being told things like live your life the best you can. I was told at one point that my life is going to be in a wheelchair. To be newly diagnosed, not knowing what's going on, with three young kids, it was a lot. There was not a lot of guidance, like try these therapies or do these things. It was just keep watching.

**Moderator:** You said you were on some SMA pages. Tell me about that. Did you go on Facebook?

**Respondent:** Yeah. The one lady, whose daughter we knew, did a lot of research and found some pages. My husband and her husband were in the army together. I found some pages on Facebook and got some information from there. At the time, I was told there were really no doctors that knew a lot about adult SMA. There was one doctor in Ohio that kind of knew a little bit about adult SMA, but I heard there was a pediatric doctor in Utah, and that's where they sent me. I went to a children's doctor in Utah.

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

**Respondent:** I think she is a neurologist.

**Moderator:** How did that go when you met with her?

**Respondent:** Very well. She was very insightful. I spoke to a dietitian there. They did some testing. I had lost my ability to climb stairs without a railing, but as they were testing me, I could do it in her office. It was probably one of the most informational doctors I had seen. They broke down SMA for me, how they think I was affected, gave me more information, a better outlook, and some dietary advice.

**Moderator:** Okay. I want to understand where you're at now, and then maybe we'll fill in between now and then. In terms of now, do you have a neurologist?

**Respondent:** I have a neurologist that I see twice a year. I'm in the process of swapping, but I see a neurologist every six months 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?

**Respondent:** Just to track my strength and things like that, to keep tabs on myself.

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

**Respondent:** I do. I just have to wait.