SMA Adult Activation Qual

(Sep 10, 2025 - 12:00pm)

(00:00:01 - 00:00:02)

**Patient:** Samantha.



(00:00:02 - 00:00:05)

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



(00:00:05 - 00:00:06)

**Patient:** Nice to meet you.



(00:00:06 - 00:00:08)

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



(00:00:08 - 00:00:08)

**Patient:** Good.



(00:00:09 - 00:01:09)

**Nancy:** 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?



(00:01:09 - 00:01:10)

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



(00:01:10 - 00:01:23)

**Nancy:** 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.



(00:01:23 - 00:01:24)

**Patient:** Okay.



(00:01:23 - 00:01:27)

**Nancy:** A ton of questions. Are are you okay with all that, everything.



(00:01:27 - 00:01:28)

**Patient:** Yes,



(00:01:27 - 00:01:28)

**Nancy:** I said?



(00:01:28 - 00:01:28)

**Patient:** Ma'am.



(00:01:28 - 00:01:29)

**Nancy:** Any question? Okay.



(00:01:29 - 00:01:29)

**Patient:** Yeah.



(00:01:30 - 00:01:35)

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



(00:01:36 - 00:01:37)

**Patient:** I have SMA.



(00:01:38 - 00:01:39)

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



(00:01:39 - 00:01:39)

**Patient:** Yes.



(00:01:40 - 00:01:47)

**Nancy:** 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?



(00:01:47 - 00:02:03)

**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.



(00:02:04 - 00:02:04)

**Nancy:** Wow.



(00:02:04 - 00:02:08)

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



(00:02:08 - 00:02:13)

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



(00:02:13 - 00:02:16)

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



(00:02:17 - 00:02:27)

**Nancy:** 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.



(00:02:27 - 00:02:27)

**Patient:** Yep.



(00:02:28 - 00:02:35)

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



(00:02:35 - 00:02:50)

**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.



(00:02:51 - 00:02:59)

**Nancy:** 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.



(00:02:59 - 00:03:04)

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



(00:03:03 - 00:03:04)

**Nancy:** Interesting.



(00:03:04 - 00:03:11)

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



(00:03:13 - 00:03:18)

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



(00:03:17 - 00:03:18)

**Patient:** Yeah.



(00:03:18 - 00:03:24)

**Nancy:** 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?



(00:03:24 - 00:03:24)

**Patient:** Yeah.



(00:03:24 - 00:03:24)

**Nancy:** I don't.



(00:03:24 - 00:03:25)

**Patient:** Yep.



(00:03:24 - 00:03:32)

**Nancy:** Know. So well, good for you. So when your type your type three SMA. Is that right?



(00:03:31 - 00:03:32)

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



(00:03:32 - 00:03:35)

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



(00:03:36 - 00:03:37)

**Patient:** October 2012.



(00:03:39 - 00:03:43)

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



(00:03:43 - 00:03:44)

**Patient:** I'm 43.



(00:03:45 - 00:03:49)

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



(00:03:49 - 00:03:50)

**Patient:** Mhmm.



(00:03:49 - 00:03:50)

**Nancy:** Am I.



(00:03:50 - 00:03:52)

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



(00:03:52 - 00:03:52)

**Nancy:** Wow.



(00:03:52 - 00:03:53)

**Patient:** I'm good at math.



(00:03:53 - 00:03:57)

**Nancy:** Me too. Me too. Me too. I was like, am I getting this right?



(00:03:57 - 00:03:58)

**Patient:** Close.



(00:03:57 - 00:04:07)

**Nancy:** 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.



(00:04:07 - 00:04:07)

**Patient:** Our.



(00:04:07 - 00:04:07)

**Nancy:** Early.



(00:04:07 - 00:04:42)

**Patient:** 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.



(00:04:43 - 00:04:50)

**Nancy:** 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.



(00:04:50 - 00:04:51)

**Patient:** Yes.



(00:04:55 - 00:04:57)

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



(00:04:58 - 00:04:59)

**Patient:** Yeah.



(00:04:58 - 00:05:04)

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



(00:05:05 - 00:05:05)

**Patient:** Mhmm.



(00:05:06 - 00:05:07)

**Nancy:** Wow.



(00:05:06 - 00:05:18)

**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.



(00:05:20 - 00:05:32)

**Nancy:** 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.



(00:05:33 - 00:05:34)

**Patient:** He was pretty.



(00:05:34 - 00:05:34)

**Nancy:** Yeah.



(00:05:34 - 00:05:58)

**Patient:** 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.



(00:05:59 - 00:06:03)

**Nancy:** Sorry. I don't know why I just giggled, but it's just intense. It's a bit like.



(00:06:03 - 00:06:04)

**Patient:** Yeah.



(00:06:03 - 00:06:04)

**Nancy:** Yeah.



(00:06:04 - 00:06:05)

**Patient:** Yep.



(00:06:05 - 00:06:14)

**Nancy:** Gosh. Had you been seeing a physical therapist or have your own physical therapist before the interaction with the the pastor's wife?



(00:06:15 - 00:07:20)

**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.



(00:07:21 - 00:07:23)

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



(00:07:23 - 00:07:24)

**Patient:** Mhmm.



(00:07:23 - 00:07:24)

**Nancy:** Wow.



(00:07:24 - 00:07:28)

**Patient:** Yeah. So I just kinda thought my weight was causing some of my issues. You.



(00:07:28 - 00:07:28)

**Nancy:** Yeah.



(00:07:28 - 00:07:32)

**Patient:** Know, maybe I was too heavy for my body frame or something like that.



(00:07:33 - 00:07:41)

**Nancy:** 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.



(00:07:41 - 00:07:45)

**Patient:** Yeah. Yep.



(00:07:47 - 00:07:49)

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



(00:07:49 - 00:07:49)

**Patient:** Right.



(00:07:53 - 00:08:00)

**Nancy:** 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.



(00:08:01 - 00:08:33)

**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?



(00:08:35 - 00:08:37)

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



(00:08:38 - 00:08:42)

**Patient:** I was worried if my kids, you know, would have SMA, you know, just.



(00:08:42 - 00:08:43)

**Nancy:** Oh,



(00:08:42 - 00:08:45)

**Patient:** Part of just kind of, you know, processing it all.



(00:08:45 - 00:08:46)

**Nancy:** Like, was.



(00:08:46 - 00:08:46)

**Patient:** Because.



(00:08:46 - 00:08:47)

**Nancy:** There a genetic thing that.



(00:08:47 - 00:08:48)

**Patient:** Mhmm.



(00:08:47 - 00:08:49)

**Nancy:** You passed that was passed down to them? I.



(00:08:49 - 00:08:50)

**Patient:** Yep.



(00:08:49 - 00:08:50)

**Nancy:** See.



(00:08:50 - 00:08:51)

**Patient:** Yep.



(00:08:53 - 00:09:01)

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



(00:09:01 - 00:09:01)

**Patient:** Yes.



(00:09:01 - 00:09:02)

**Nancy:** Type one?



(00:09:02 - 00:09:03)

**Patient:** Yes.



(00:09:03 - 00:09:05)

**Nancy:** Yeah. And that was your one example of.



(00:09:06 - 00:09:06)

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



(00:09:06 - 00:09:07)

**Nancy:** SMA?



(00:09:06 - 00:09:08)

**Patient:** Knew. Mhmm. Yeah.



(00:09:08 - 00:09:14)

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



(00:09:15 - 00:09:42)

**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.



(00:09:43 - 00:09:44)

**Nancy:** Oh, at the.



(00:09:44 - 00:09:44)

**Patient:** I.



(00:09:44 - 00:09:46)

**Nancy:** Same at the same place? Or.



(00:09:46 - 00:09:52)

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



(00:09:53 - 00:09:57)

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



(00:09:57 - 00:10:02)

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



(00:10:02 - 00:10:06)

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



(00:10:07 - 00:10:19)

**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.



(00:10:19 - 00:10:20)

**Nancy:** Wow.



(00:10:19 - 00:10:23)

**Patient:** Pushed my insurance to go out there, because I did.



(00:10:23 - 00:10:24)

**Nancy:** Wow.



(00:10:23 - 00:10:43)

**Patient:** 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.



(00:10:44 - 00:10:49)

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



(00:10:50 - 00:11:22)

**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.



(00:11:22 - 00:11:22)

**Nancy:** Yeah.



(00:11:22 - 00:11:27)

**Patient:** Out the next wheelchair that you would like. You know? That's what it's being presented to me as.



(00:11:27 - 00:11:27)

**Nancy:** Wow.



(00:11:27 - 00:11:36)

**Patient:** 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.



(00:11:36 - 00:11:36)

**Nancy:** Wow.



(00:11:36 - 00:11:43)

**Patient:** 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.



(00:11:43 - 00:11:51)

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



(00:11:51 - 00:11:51)

**Patient:** On.



(00:11:51 - 00:11:52)

**Nancy:** Something?



(00:11:51 - 00:11:52)

**Patient:** Facebook,



(00:11:52 - 00:11:52)

**Nancy:** Or.



(00:11:52 - 00:12:46)

**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.



(00:12:46 - 00:12:46)

**Nancy:** And this is.



(00:12:46 - 00:12:47)

**Patient:** Was.



(00:12:46 - 00:12:47)

**Nancy:** A neurologist.



(00:12:47 - 00:12:48)

**Patient:** An.



(00:12:47 - 00:12:48)

**Nancy:** Who you were told.



(00:12:48 - 00:12:49)

**Patient:** Adult.



(00:12:49 - 00:12:49)

**Nancy:** Was it.



(00:12:50 - 00:12:52)

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



(00:12:52 - 00:12:56)

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



(00:12:57 - 00:13:53)

**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.



(00:13:54 - 00:14:12)

**Nancy:** 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.



(00:14:12 - 00:14:13)

**Patient:** Mhmm.



(00:14:12 - 00:14:13)

**Nancy:** Have a.



(00:14:20 - 00:14:40)

**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.



(00:14:42 - 00:14:44)

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



(00:14:45 - 00:14:54)

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



(00:14:55 - 00:15:02)

**Nancy:** 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?



(00:15:03 - 00:15:05)

**Patient:** I do. I just.



(00:15:05 - 00:15:05)

**Nancy:** Tell.



(00:15:05 - 00:15:05)

**Patient:** Have.



(00:15:05 - 00:15:05)

**Nancy:** Me.



(00:15:05 - 00:15:05)

**Patient:** To wait.



(00:15:05 - 00:15:06)

**Nancy:** Why.

