SMA Access Promo Messaging Qual

(Oct 21, 2025 - 1:30pm)

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

**Laurie:** Hi. Nice to meet you.



(00:00:04 - 00:00:12)

**Stacey:** I see we are joined by your furry baby there. Oh my goodness.



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

**Laurie:** This is Daisy.



(00:00:14 - 00:00:16)

**Stacey:** Daisy is beautiful.



(00:00:16 - 00:00:17)

**Laurie:** Thank you.



(00:00:17 - 00:00:17)

**Stacey:** Aw.



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

**Laurie:** God.



(00:00:18 - 00:00:20)

**Stacey:** What kind of cat is she.



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

**Laurie:** Besides trouble, she's.



(00:00:23 - 00:00:23)

**Stacey:** Besides.



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

**Laurie:** A Cornish.



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

**Stacey:** Trouble?



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

**Laurie:** Mix.



(00:00:25 - 00:00:29)

**Stacey:** Oh, okay. She's very unique, very beautiful. I.



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

**Laurie:** They.



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

**Stacey:** Love.



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

**Laurie:** Have,



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

**Stacey:** That.



(00:00:29 - 00:00:36)

**Laurie:** Like, curl like, waves, ripples, and they don't have the top guard hairs, which a lot of people are allergic to. So they.



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

**Stacey:** Okay.



(00:00:36 - 00:00:42)

**Laurie:** Just feel like soft, soft kind of bunny almost. And as you can see, humongous ears.



(00:00:44 - 00:01:00)

**Stacey:** Yeah. I have a I have two cats as well. All their deer regular garden variety chunk of monks. But my dog, I'm a little chihuahua with these giant giant ears, so I am a I'm a I'm a sucker for livid years.



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

**Laurie:** Well, you've got them. So.



(00:01:03 - 00:01:09)

**Stacey:** Oh my god. Yes. She does. That's awesome. Well, she's very welcome to be here. So pleased.



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

**Laurie:** Thank.



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

**Stacey:** To.



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

**Laurie:** You.



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

**Stacey:** Pleased.



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

**Laurie:** Yeah. Well,



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

**Stacey:** To meet.



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

**Laurie:** I can't.



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

**Stacey:** Her as.



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

**Laurie:** Get rid.



(00:01:10 - 00:01:11)

**Stacey:** Well.



(00:01:10 - 00:01:11)

**Laurie:** Of her. So.



(00:01:11 - 00:01:22)

**Stacey:** Right. Right. Yes. Understood. Yeah. I totally get it. Well, so let me give you a little background so you know what we're up to. First of.



(00:01:22 - 00:01:22)

**Laurie:** Mhmm.



(00:01:22 - 00:01:23)

**Stacey:** All, have you done this kind of thing before?



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

**Laurie:** Yes.



(00:01:25 - 00:01:26)

**Stacey:** Okay. Alright. So this.



(00:01:26 - 00:01:26)

**Laurie:** Yeah.



(00:01:26 - 00:01:52)

**Stacey:** Will probably all sound familiar. Obviously, our topic is SMA. We will be I'll ask you some things, you know, about you and and your life, and then the majority of our time is going to be spent reviewing some materials. So I'll tell you a little bit more about them when we get there, but really just hoping for your candor, I am an unbiased third party researcher, so hoping you'll share your very, you know, candid, comments with me.



(00:01:52 - 00:01:53)

**Laurie:** Absolutely.



(00:01:53 - 00:01:54)

**Stacey:** We.



(00:01:53 - 00:01:53)

**Laurie:** Yep.



(00:01:54 - 00:02:08)

**Stacey:** Will be recording. We also have some listeners from the research team in the background, And, we also wanna make you aware that we have the requirement to report side effects, adverse events, or side effects,



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

**Laurie:** Mhmm.



(00:02:08 - 00:02:17)

**Stacey:** If they pertain to the study sponsor. So to the best of our ability, let's avoid discussing any particular issues that you've had with any medication that you've taken,



(00:02:16 - 00:02:17)

**Laurie:** Yep.



(00:02:17 - 00:02:19)

**Stacey:** But not to worry if it does if it does come up.



(00:02:19 - 00:02:20)

**Laurie:** Okay.



(00:02:20 - 00:02:25)

**Stacey:** And, gosh, I think that covers everything. Any questions?



(00:02:26 - 00:02:27)

**Laurie:** No?



(00:02:27 - 00:02:32)

**Stacey:** Okay. Let's dive in. Can you start by just telling me a little bit about you?



(00:02:33 - 00:03:04)

**Laurie:** Sure. I am, 56 years old. I've been married for thirty five years to my, English husband. Lived in England for fifteen years and have lived back in The States now for about twenty. We have two kids, a 20 year old girl and a 16 year old boy. And my husband works. I'm just a home homemaker. Just a homemaker. That sounded terrible.



(00:03:04 - 00:03:05)

**Stacey:** I I you.



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

**Laurie:** I.



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

**Stacey:** Took.



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

**Laurie:** Didn't.



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

**Stacey:** The words.



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

**Laurie:** Even.



(00:03:06 - 00:03:07)

**Stacey:** Right out of my mouth. Yes.



(00:03:09 - 00:03:12)

**Laurie:** I just meant I stay home. I don't I don't go out to work. But I have.



(00:03:12 - 00:03:13)

**Stacey:** Understood.



(00:03:12 - 00:03:18)

**Laurie:** An Etsy shop. I sell, I don't sell a lot, but I sell vintage clothing on Etsy.



(00:03:18 - 00:03:19)

**Stacey:** Mhmm.



(00:03:19 - 00:03:19)

**Laurie:** So,



(00:03:19 - 00:03:33)

**Stacey:** Good. Okay. Thank you. Tell me about SMA, that part of your life. How how would you talk about your health currently?



(00:03:35 - 00:04:06)

**Laurie:** I mean, it's not great. I don't think anybody with SMAs can say their health is great. It's it's it affects every aspect of my life from from waking to bed at night. I mean, it's it's awful. But I think, you know, you you learn to deal with it and you make the best of it and you focus on the good stuff. And it's debilitating and it's exhausting and it's it's a tough disease.



(00:04:06 - 00:04:07)

**Stacey:** Mhmm.



(00:04:06 - 00:04:07)

**Laurie:** But I'm.



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

**Stacey:** Got.



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

**Laurie:** Lucky.



(00:04:07 - 00:04:08)

**Stacey:** It.



(00:04:07 - 00:04:10)

**Laurie:** That type three because it could be a lot worse. So.



(00:04:11 - 00:04:16)

**Stacey:** Thank you for your candor with that.



(00:04:15 - 00:04:16)

**Laurie:** Sorry?



(00:04:16 - 00:04:17)

**Stacey:** I appreciate it.



(00:04:17 - 00:04:33)

**Laurie:** Yeah. Anyone that says that they they don't mind having SMA or as SMA has made them who they are, in my opinion, is bullshit. Excuse me. Language. But because I would get rid of this in a heartbeat if I could.



(00:04:33 - 00:04:34)

**Stacey:** Right.



(00:04:34 - 00:04:37)

**Laurie:** And I don't think I don't think who I am would change.



(00:04:37 - 00:04:38)

**Stacey:** Mhmm.



(00:04:38 - 00:04:40)

**Laurie:** I am who I am with me, not because of the disease.



(00:04:40 - 00:04:41)

**Stacey:** Yep.



(00:04:41 - 00:04:42)

**Laurie:** And I.



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

**Stacey:** Yep.



(00:04:42 - 00:04:43)

**Laurie:** I don't buy that for a second.



(00:04:44 - 00:05:10)

**Stacey:** Mhmm. I I appreciate you, Lori. We're gonna get along just fine here. You you keep like, I love that you're just saying it out as, like I I appreciate that very much. Tell me about treatment and what you're currently being treated with and if you've ever switched your treatment.



(00:05:11 - 00:05:14)

**Laurie:** Right. I'm currently being treated with SPINRAZA.



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

**Stacey:** K.



(00:05:16 - 00:05:27)

**Laurie:** I started SPINRAZA. It came out in December 2016. That's when it was approved. Because I remember I was on the phone with my friend who has SMA, and we were both in tier did. So.



(00:05:27 - 00:05:27)

**Stacey:** K.



(00:05:27 - 00:05:58)

**Laurie:** Eleven months to get approved. So I started November 2017, and I stayed on it until, I think, was June 2020. I felt like I had plateaued kind of, and I wasn't sure if I was getting everything I wanted to get out of it and if RISD had come on the market. So my doctor and I made the decision to why don't we take a break from SPINRAZA, try a VRISD? Maybe it'll work better. I mean, I'll you know, it's worth a try.



(00:05:59 - 00:05:59)

**Stacey:** Mhmm.



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

**Laurie:** So I was on a VRISD. Hang on. I wrote it down. Yeah. I started a VRISD September 2020,



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

**Stacey:** K.



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

**Laurie:** And I took it until August 2021.



(00:06:09 - 00:06:10)

**Stacey:** Got it.



(00:06:11 - 00:06:16)

**Laurie:** Stopped it and then restarted SPINRAZA in June 2022.



(00:06:16 - 00:06:17)

**Stacey:** Got it. So.



(00:06:17 - 00:06:17)

**Laurie:** And on.



(00:06:17 - 00:06:21)

**Stacey:** You really did start up RISD very quickly after it was made.



(00:06:21 - 00:06:22)

**Laurie:** I.



(00:06:21 - 00:06:22)

**Stacey:** About,



(00:06:22 - 00:06:22)

**Laurie:** Did.



(00:06:22 - 00:06:22)

**Stacey:** Like,



(00:06:22 - 00:06:23)

**Laurie:** Yeah.



(00:06:22 - 00:06:23)

**Stacey:** Two months.



(00:06:24 - 00:06:25)

**Laurie:** I've always said,



(00:06:25 - 00:06:25)

**Stacey:** Got.



(00:06:25 - 00:06:33)

**Laurie:** Like, whatever medicine, like, comes on the market, I will try it. Like, it's I'm not gonna know, and I'm gonna wonder if I don't at least give it a shot.



(00:06:34 - 00:06:46)

**Stacey:** It. Well, can you say just a little bit more about was it so so it was the idea of giving it a shot as well as feeling that you had plateaued.



(00:06:45 - 00:06:46)

**Laurie:** Yeah.



(00:06:46 - 00:06:47)

**Stacey:** Those were.



(00:06:46 - 00:07:08)

**Laurie:** And and I think I think because because I wasn't sure that I was getting as much as I wanted out of SPINRAZA, as soon as the new drug came out, also, you know, a syringe of five mil or whatever it was a day as opposed to a intrathecal injection in my spinal cord three times a year, I would take every day of the week,



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

**Stacey:** Yep.



(00:07:09 - 00:07:12)

**Laurie:** Because that's a pain. The administration process.



(00:07:11 - 00:07:12)

**Stacey:** Mhmm.



(00:07:12 - 00:07:24)

**Laurie:** Is a pain with literally with SPINRAZA. So and and, also, like, I I would kick myself because I would always think, well, what if if RISD worked better? Like, I don't know if I don't try.



(00:07:24 - 00:07:25)

**Stacey:** Okay. Got.



(00:07:25 - 00:07:26)

**Laurie:** So I.



(00:07:25 - 00:07:26)

**Stacey:** It.



(00:07:26 - 00:07:27)

**Laurie:** Want to try.



(00:07:30 - 00:07:35)

**Stacey:** Just under a year, you switched back to SPINRAZA. Tell me about making that decision.



(00:07:37 - 00:07:40)

**Laurie:** If RISD was not working for me.



(00:07:40 - 00:07:40)

**Stacey:** K.



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

**Laurie:** At all, It was probably having the opposite effect.



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

**Stacey:** Mhmm.



(00:07:45 - 00:08:02)

**Laurie:** So, I know we see well, I don't know if it's a side effect, but I don't think it was a side effect of the actual drug per se. But because the drug wasn't working, I noticed my upper body losing strength while I was on a risdi.



(00:08:02 - 00:08:03)

**Stacey:** Got it.



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

**Laurie:** So that was enough for me. That was,



(00:08:04 - 00:08:05)

**Stacey:** Mhmm.



(00:08:04 - 00:08:06)

**Laurie:** Like, done. I'm off.



(00:08:07 - 00:08:14)

**Stacey:** Got it. Got it. And so your okay. Got it. So when you said not working for you, that's what you meant that your upper.



(00:08:14 - 00:08:15)

**Laurie:** Yes.



(00:08:14 - 00:08:16)

**Stacey:** Body was losing strength.



(00:08:15 - 00:08:16)

**Laurie:** Yes.



(00:08:16 - 00:08:16)

**Stacey:** Okay.



(00:08:16 - 00:08:20)

**Laurie:** Yep. It wasn't a side effect like stomachaches or what.



(00:08:20 - 00:08:20)

**Stacey:** Right.



(00:08:20 - 00:08:22)

**Laurie:** You know, it just it just wasn't effective for.



(00:08:22 - 00:08:22)

**Stacey:** Yep.



(00:08:22 - 00:08:23)

**Laurie:** Me. And.



(00:08:23 - 00:08:24)

**Stacey:** Understood.



(00:08:23 - 00:08:26)

**Laurie:** I know there are people it it is very effective for,



(00:08:26 - 00:08:27)

**Stacey:** Mhmm.



(00:08:26 - 00:08:28)

**Laurie:** But it just wasn't for me.



(00:08:30 - 00:08:34)

**Stacey:** Got it. Alright. And so you went back to Spinraza.



(00:08:34 - 00:08:35)

**Laurie:** Yeah.



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

**Stacey:** And.



(00:08:35 - 00:08:36)

**Laurie:** Eventually. Yeah.



(00:08:36 - 00:08:38)

**Stacey:** Eventually okay. Not right away.



(00:08:38 - 00:08:55)

**Laurie:** Took a well, hang on. So if I August, it took, like, nine or ten months, part of which was getting insurance preapproval and part of which was because I pissed my doctor off because I stopped at Virsd without telling him.



(00:08:56 - 00:08:56)

**Stacey:** Got.



(00:08:56 - 00:08:56)

**Laurie:** And.



(00:08:56 - 00:08:57)

**Stacey:** It.



(00:08:56 - 00:08:57)

**Laurie:** He.



(00:08:57 - 00:08:57)

**Stacey:** Okay.



(00:08:57 - 00:09:21)

**Laurie:** He was I loved him, but he was like a grumpy old man, who has since retired. And he got and I and he was right you know, rightfully annoyed with me because I shouldn't have done it without speaking to him. But, like, I know my body best, and I knew it wasn't working, and I knew it was the right decision to make for me. I just shouldn't But he had a little bit of a hissy fit and made me wait a few months.



(00:09:22 - 00:09:24)

**Stacey:** Got it. So.



(00:09:23 - 00:09:24)

**Laurie:** Yeah.



(00:09:24 - 00:09:31)

**Stacey:** Meaning before he would prescribe, and then you had to wait on top of that for insurance preapproval?



(00:09:31 - 00:09:31)

**Laurie:** Yeah.



(00:09:31 - 00:09:32)

**Stacey:** Okay.



(00:09:31 - 00:09:33)

**Laurie:** Yep. Yeah.



(00:09:34 - 00:09:35)

**Stacey:** Okay.



(00:09:35 - 00:09:38)

**Laurie:** But I was just happy to RISD, so it didn't bother me.



(00:09:38 - 00:09:47)

**Stacey:** Got it. Okay. Tell me about the insurance reapproval challenge that you experienced.



(00:09:49 - 00:10:18)

**Laurie:** To be honest, I don't remember the actual details. I just knew I think the first time we applied for it, it got denied, and then we just had to go through the appeal process, and then it was approved after that. Luckily, my, we get our insurance through my husband's job, and they have a really good, advocate in HR that deals with the company and, like, speaks up for the employees and the families and stuff. So that was a big help.



(00:10:18 - 00:10:22)

**Stacey:** Okay. I was gonna ask if you had gotten any help with that.



(00:10:22 - 00:10:24)

**Laurie:** Yeah. Yeah.



(00:10:24 - 00:10:25)

**Stacey:** Okay. Now I.



(00:10:24 - 00:10:25)

**Laurie:** They.



(00:10:25 - 00:10:25)

**Stacey:** Know.



(00:10:25 - 00:10:25)

**Laurie:** Really.



(00:10:25 - 00:10:26)

**Stacey:** That.



(00:10:25 - 00:10:27)

**Laurie:** Use skills with that kind of stuff. They make.



(00:10:27 - 00:10:28)

**Stacey:** Okay.



(00:10:27 - 00:10:28)

**Laurie:** Things a lot easier.



(00:10:29 - 00:10:43)

**Stacey:** Got it. I know that the manufacturers, most of them offer, like, support programs. Did you have any help from the manufacturer with that reapproval process or just from the HR?



(00:10:43 - 00:10:52)

**Laurie:** I I don't know that I had help with the reapproval process from the we have, like, a fam, like, a family access manager with.



(00:10:52 - 00:10:52)

**Stacey:** K.



(00:10:52 - 00:11:11)

**Laurie:** Biogen, but they're a huge help with all the other stuff, like, getting making sure the drug's at the facility and just helping with any issues. Like, I'm in a co pay assist program, so they help with making sure the bills get taken care of and that kind.



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

**Stacey:** Okay.



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

**Laurie:** Of stuff.



(00:11:11 - 00:11:13)

**Stacey:** Got it. Alright.



(00:11:12 - 00:11:14)

**Laurie:** I would hate to do this without them, honestly.



(00:11:15 - 00:11:16)

**Stacey:** Okay.



(00:11:16 - 00:11:25)

**Laurie:** Phenomenal. They they really are a kinda shining example of the company. Like, they make the company look good, the fans. They really do.



(00:11:25 - 00:11:27)

**Stacey:** Okay. That's that's really.



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

**Laurie:** My.



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

**Stacey:** Helpful.



(00:11:27 - 00:11:28)

**Laurie:** Fans.



(00:11:27 - 00:11:28)

**Stacey:** To understand.



(00:11:28 - 00:11:31)

**Laurie:** Wonderful. I love him to death.



(00:11:31 - 00:11:39)

**Stacey:** What kind of experience did you have with Avrista's equivalent support program?



(00:11:40 - 00:11:58)

**Laurie:** I didn't I don't feel like I had as much of an interaction, and maybe that's because it was just a matter of getting medicine delivered. I can't remember how often we used to get it, if it was monthly or I don't know. I get, like, a box with the ice packs and cooler. And,



(00:11:58 - 00:11:58)

**Stacey:** Mhmm.



(00:11:58 - 00:12:16)

**Laurie:** But, I mean, they were very good. They you know, we never missed a dose. They always had the medicine there on time, never had any issues. But it was a simpler procedure, whereas with Raza, it's booking the radiologist, booking the hospital appointment. There's more to it.



(00:12:16 - 00:12:17)

**Stacey:** Mhmm. K.



(00:12:17 - 00:12:18)

**Laurie:** And.



(00:12:17 - 00:12:18)

**Stacey:** Got.



(00:12:18 - 00:12:18)

**Laurie:** The.



(00:12:18 - 00:12:18)

**Stacey:** It.



(00:12:18 - 00:12:24)

**Laurie:** Separate pills coming in from the hospital, from the radiologist, whereas it was just a drug with a first date.



(00:12:24 - 00:12:24)

**Stacey:** Yeah.



(00:12:24 - 00:12:24)

**Laurie:** So.



(00:12:24 - 00:12:26)

**Stacey:** Okay. Okay.



(00:12:25 - 00:12:26)

**Laurie:** It was much.



(00:12:26 - 00:12:37)

**Stacey:** Got it. But as far as you recall, the insurance reapproval process, it was more the, the advocate in the HR your husband's HR department that.



(00:12:37 - 00:12:42)

**Laurie:** It may have been the the fam with with Biogen helped out as well, but I don't I don't honestly.



(00:12:42 - 00:12:43)

**Stacey:** Yeah.



(00:12:42 - 00:12:43)

**Laurie:** Recall.



(00:12:43 - 00:12:57)

**Stacey:** Okay. No problem. And how since then, any insurance issues since getting preapproved for SPINRAZA?



(00:12:56 - 00:12:57)

**Laurie:** No.



(00:12:57 - 00:12:58)

**Stacey:** Okay.



(00:12:58 - 00:12:59)

**Laurie:** No. Not since.



(00:12:59 - 00:12:59)

**Stacey:** Got.



(00:12:59 - 00:12:59)

**Laurie:** Then.



(00:12:59 - 00:13:07)

**Stacey:** It. Now just to go backwards, when you went from SPINRAZA to Evristi, did you have any access issues at that time?



(00:13:08 - 00:13:10)

**Laurie:** Do I have any I'm sorry. What?



(00:13:10 - 00:13:12)

**Stacey:** Oh, sorry. Access in short.



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

**Laurie:** Oh, I.



(00:13:13 - 00:13:13)

**Stacey:** Forgive.



(00:13:13 - 00:13:13)

**Laurie:** Thought.



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

**Stacey:** Me.



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

**Laurie:** You said.



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

**Stacey:** Access.



(00:13:14 - 00:13:15)

**Laurie:** Excess. I'm sorry. I.



(00:13:15 - 00:13:16)

**Stacey:** No.



(00:13:15 - 00:13:16)

**Laurie:** Heard excess.



(00:13:16 - 00:13:17)

**Stacey:** No. No.



(00:13:17 - 00:13:18)

**Laurie:** I.



(00:13:17 - 00:13:18)

**Stacey:** No worries.



(00:13:18 - 00:13:25)

**Laurie:** Don't recall whether Adversity was approved first time or not. I don't I don't think I had issues.



(00:13:25 - 00:13:26)

**Stacey:** Mhmm.



(00:13:25 - 00:13:27)

**Laurie:** Getting Adversity approved,



(00:13:28 - 00:13:28)

**Stacey:** Got.



(00:13:28 - 00:13:28)

**Laurie:** But.



(00:13:28 - 00:13:29)

**Stacey:** It.



(00:13:28 - 00:13:30)

**Laurie:** I don't I don't recall exactly.



(00:13:30 - 00:13:30)

**Stacey:** Okay.



(00:13:30 - 00:13:30)

**Laurie:** It was a.



(00:13:31 - 00:13:32)

**Stacey:** Okay.



(00:13:31 - 00:13:32)

**Laurie:** It was COVID.



(00:13:32 - 00:13:32)

**Stacey:** That's helpful.



(00:13:32 - 00:13:34)

**Laurie:** It was during COVID, so.



(00:13:33 - 00:13:34)

**Stacey:** Ah, okay.



(00:13:34 - 00:13:35)

**Laurie:** Mostly.



(00:13:34 - 00:13:35)

**Stacey:** Yeah.



(00:13:35 - 00:13:37)

**Laurie:** Blacked all of that out, haven't we?



(00:13:37 - 00:13:40)

**Stacey:** Yeah. For sure. Alright.



(00:13:40 - 00:13:40)

**Laurie:** Oh,



(00:13:40 - 00:13:40)

**Stacey:** So.



(00:13:40 - 00:13:41)

**Laurie:** Yes.



(00:13:40 - 00:13:56)

**Stacey:** Then let's let's take a minute more on then the reapproval challenges. What do you recall about what what was required? Like, what what did you or the doctor you know,



(00:13:57 - 00:13:58)

**Laurie:** I.



(00:13:58 - 00:13:59)

**Stacey:** Did did you guys have.



(00:13:59 - 00:13:59)

**Laurie:** This.



(00:13:59 - 00:13:59)

**Stacey:** To, like,



(00:13:59 - 00:13:59)

**Laurie:** Is the.



(00:13:59 - 00:14:00)

**Stacey:** Provide?



(00:13:59 - 00:14:01)

**Laurie:** Reapprove for.



(00:14:01 - 00:14:01)

**Stacey:** Yeah.



(00:14:01 - 00:14:25)

**Laurie:** SPINRAZA. I think, basically, what they had said was that, the typical, like, not medically necessary, like, kinda thing. And it basically, I think all it required was, a letter of medical necessity from the doctor, which I believe I I think I don't know if I wrote it or I found a form online that I because you can find all kinds of.



(00:14:25 - 00:14:26)

**Stacey:** Right. Mhmm.



(00:14:26 - 00:14:41)

**Laurie:** Those letters. And there's a good, resource. There was a good resource on Facebook. I don't know if it's still there. With a a lady who made up lots of, letters of medical necessity for different things, for equipped durable medical equipment, for cough.



(00:14:40 - 00:14:41)

**Stacey:** Got.



(00:14:41 - 00:14:41)

**Laurie:** Assists,



(00:14:41 - 00:14:41)

**Stacey:** It.



(00:14:41 - 00:14:46)

**Laurie:** For wheelchairs, for all that kind of stuff. And there was a good one just for the treatment for.



(00:14:46 - 00:14:47)

**Stacey:** Okay.



(00:14:46 - 00:14:47)

**Laurie:** SPINRAZA,



(00:14:47 - 00:14:47)

**Stacey:** Okay.



(00:14:47 - 00:14:50)

**Laurie:** And I might have used that. I can't remember.



(00:14:53 - 00:15:01)

**Stacey:** Are you involved with any s m with the SMA community in a in any way, whether on.



(00:15:01 - 00:15:02)

**Laurie:** Yeah. Yeah.



(00:15:02 - 00:15:02)

**Stacey:** It sounds.



(00:15:02 - 00:15:02)

**Laurie:** I'm.



(00:15:02 - 00:15:02)

**Stacey:** Like.



(00:15:02 - 00:15:03)

**Laurie:** In the.



(00:15:02 - 00:15:03)

**Stacey:** Facebook.



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

**Laurie:** Local part of, Cure SMA.



(00:15:05 - 00:15:07)

**Stacey:** Mhmm. Got it.



(00:15:07 - 00:15:11)

**Laurie:** The yep. We have our walk coming up in about three weeks.



(00:15:11 - 00:15:12)

**Stacey:** Okay.



(00:15:12 - 00:15:14)

**Laurie:** We do a walk and roll every year.



(00:15:14 - 00:15:16)

**Stacey:** Got it. Oh, I like that walking wall.



(00:15:17 - 00:15:18)

**Laurie:** Yeah. It's fun.



(00:15:19 - 00:15:23)

**Stacey:** Any of the Facebook groups or any other just just cute.



(00:15:23 - 00:15:26)

**Laurie:** Just like the Cure SMA page, and there's,



(00:15:26 - 00:15:26)

**Stacey:** Got.



(00:15:26 - 00:15:27)

**Laurie:** Adult.



(00:15:26 - 00:15:27)

**Stacey:** It. Okay.



(00:15:27 - 00:15:28)

**Laurie:** SMA and and.



(00:15:28 - 00:15:28)

**Stacey:** Okay.



(00:15:28 - 00:15:36)

**Laurie:** Women of SMA, and there's different I'm not overly active on them, but I I I see what goes in, and I'll comment.



(00:15:35 - 00:15:36)

**Stacey:** Yep.



(00:15:36 - 00:15:37)

**Laurie:** Him.



(00:15:39 - 00:15:44)

**Stacey:** And I'm curious if you just happen to be aware of any treatments in development.



(00:15:46 - 00:15:47)

**Laurie:** Oh, yeah. Yeah.



(00:15:47 - 00:15:48)

**Stacey:** Okay. What are you aware of?



(00:15:49 - 00:16:00)

**Laurie:** I'm aware of the, I I don't know if it's out already because I'm not on a RISD. My sister is. She would know. But I know a VRSD comes in tablet form now.



(00:16:00 - 00:16:01)

**Stacey:** Yes.



(00:16:01 - 00:16:01)

**Laurie:** Must.



(00:16:01 - 00:16:01)

**Stacey:** It is.



(00:16:01 - 00:16:01)

**Laurie:** Be.



(00:16:01 - 00:16:01)

**Stacey:** Out.



(00:16:01 - 00:16:02)

**Laurie:** Such.



(00:16:01 - 00:16:02)

**Stacey:** Now. Yep.



(00:16:02 - 00:16:06)

**Laurie:** A huge, huge advantage for people on that medicine.



(00:16:05 - 00:16:06)

**Stacey:** Mhmm.



(00:16:06 - 00:16:14)

**Laurie:** I can't And SPINRAZA was supposed to. It's been out already with the larger dose for adults.



(00:16:14 - 00:16:14)

**Stacey:** Mhmm.



(00:16:17 - 00:16:40)

**Laurie:** I'm not exactly sure what's going on, but I'm pretty sure it has something to do with the mess is the federal government at the moment. So and I know there's another drug. I know ZOLGENSMA, I think, is gonna be approved for up to the age of 17. I don't know if that's which obviously doesn't help me. But it's it's nice for.



(00:16:40 - 00:16:41)

**Stacey:** Yeah.



(00:16:40 - 00:16:42)

**Laurie:** The it's it's gonna help.



(00:16:42 - 00:16:43)

**Stacey:** Yeah.



(00:16:43 - 00:17:02)

**Laurie:** And then there's another one. I think Scholar Rock have a drug coming out called the pipromab. I don't know how you pronounce it, which is supposed to be taken with it's like a addendum, like an extra treatment on the muscles as opposed to the the genetic component. So.



(00:17:02 - 00:17:03)

**Stacey:** Where.



(00:17:02 - 00:17:03)

**Laurie:** It sounds.



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

**Stacey:** Do.



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

**Laurie:** Like.



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

**Stacey:** You.



(00:17:03 - 00:17:06)

**Laurie:** A lot going on, but not much is happening, kind.



(00:17:06 - 00:17:06)

**Stacey:** Right.



(00:17:06 - 00:17:06)

**Laurie:** Of.



(00:17:06 - 00:17:08)

**Stacey:** Now I hear you. How.



(00:17:08 - 00:17:08)

**Laurie:** So.



(00:17:08 - 00:17:12)

**Stacey:** Do you where do you get your information from about new treatments?



(00:17:12 - 00:17:13)

**Laurie:** Is from SURE SMA.



(00:17:13 - 00:17:14)

**Stacey:** Yep. K.



(00:17:14 - 00:17:18)

**Laurie:** They just had, they do a Summit of Strength.



(00:17:19 - 00:17:19)

**Stacey:** Okay.



(00:17:19 - 00:17:22)

**Laurie:** All over the country, and they just had the Orlando one recently.



(00:17:22 - 00:17:23)

**Stacey:** Got it.



(00:17:23 - 00:17:25)

**Laurie:** We attended that at Disney World.



(00:17:25 - 00:17:26)

**Stacey:** Okay.



(00:17:26 - 00:17:27)

**Laurie:** So.



(00:17:27 - 00:17:39)

**Stacey:** Okay. Thank you for all that background. Really, really, really helpful. I'm gonna shift gears because I wanna start to share the materials with you. So I wanna tell you more about what you'll see.



(00:17:39 - 00:17:39)

**Laurie:** Yep.



(00:17:39 - 00:17:58)

**Stacey:** I have a series of messages that have been developed for individuals and families, you know, adults and also parents of children with SMA. And the messages are broken into four categories, so we'll just go one category at a time.



(00:17:58 - 00:17:58)

**Laurie:** Mhmm.



(00:17:59 - 00:18:22)

**Stacey:** These are draft messages. They have not yet been polished or perfected. That's kind of the point of this research is to get some feedback on these draft ideas. In fact, you will notice even in some cases that very similar ideas like, you'll you'll see, that the same idea may be written a different way sometimes. Again, just trying out different ways of communicating these.



(00:18:22 - 00:18:22)

**Laurie:** So.



(00:18:22 - 00:18:23)

**Stacey:** Things.



(00:18:22 - 00:18:31)

**Laurie:** When you say messages, these are things that would be, like, advertisements, like, for magazines or online? Or.



(00:18:32 - 00:18:37)

**Stacey:** These are very raw they are very raw messages that could be used in a lot of different.



(00:18:37 - 00:18:38)

**Laurie:** Okay.



(00:18:37 - 00:18:38)

**Stacey:** Ways.



(00:18:38 - 00:18:38)

**Laurie:** Okay.



(00:18:38 - 00:18:55)

**Stacey:** On a website, in a brochure, in maybe I don't think these are necessarily destined for an advertising scenario, but certainly more perhaps in a an awareness or educational.



(00:18:55 - 00:18:56)

**Laurie:** Okay.



(00:18:55 - 00:18:59)

**Stacey:** Idea. You'll I think they'll make make sense when you start to see.



(00:18:59 - 00:19:00)

**Laurie:** Okay.



(00:18:59 - 00:19:10)

**Stacey:** Them. For each category, I'm gonna bring it up on the screen, but also just wanna give you, like, a little sentence or two to have in mind before you read them. So.



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

**Laurie:** Okay.



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

**Stacey:** Let me just share my screen. Alright. You should be.



Screen Shared @ 00:19:20 by Stacey



(00:19:20 - 00:19:22)

**Stacey:** Seeing just it says welcome at this point.



(00:19:24 - 00:19:25)

**Laurie:** Yep.



(00:19:25 - 00:19:41)

**Stacey:** Okay. So here's our first category. Just to read this little blurb first. So this first set of messages are related to this company's legacy and experience in SMA. So just wanted you to have that in mind. So please go ahead and read this first set.



(00:19:41 - 00:19:58)

**Laurie:** That's Okay.



(00:20:00 - 00:20:08)

**Stacey:** What are what are your thoughts? I'm curious just your reaction to this first collection of messages. What thoughts are impressions were?



(00:20:08 - 00:20:16)

**Laurie:** It seems like a good amount of of information given out in a small amount of typeface.



(00:20:16 - 00:20:17)

**Stacey:** Mhmm. Mhmm.



(00:20:17 - 00:20:20)

**Laurie:** Seems like there's a lot of good information in in there.



(00:20:21 - 00:20:27)

**Stacey:** Got it. And when you describe it as good information, how so? Like, what what makes it good information,



(00:20:26 - 00:20:27)

**Laurie:** Like,



(00:20:27 - 00:20:27)

**Stacey:** Or what's.



(00:20:27 - 00:20:27)

**Laurie:** It's it's.



(00:20:27 - 00:20:27)

**Stacey:** Good about.



(00:20:27 - 00:20:28)

**Laurie:** Hitting.



(00:20:27 - 00:20:28)

**Stacey:** It?



(00:20:28 - 00:20:35)

**Laurie:** On on the, important things. Like, in the first message, it's it's talking about how they collaborate with the SMA community.



(00:20:35 - 00:20:36)

**Stacey:** Mhmm.



(00:20:35 - 00:20:45)

**Laurie:** So it's showing that they get input from patients and doctors and that kind of thing, and that they're listening because it says reflect your feedback.



(00:20:45 - 00:20:47)

**Stacey:** Mhmm. Got.



(00:20:46 - 00:20:47)

**Laurie:** So that tells.



(00:20:47 - 00:20:47)

**Stacey:** It.



(00:20:47 - 00:20:50)

**Laurie:** Me that they're talking to the patients and asking what works for them.



(00:20:51 - 00:21:02)

**Stacey:** Mhmm. And what does that say to you? Like, the fact that they're collaborating, the fact that they're listening, like, what feeling or impression does that give you?



(00:21:02 - 00:21:06)

**Laurie:** I think it would give me more trust in the company and.



(00:21:05 - 00:21:06)

**Stacey:** Mhmm.



(00:21:06 - 00:21:13)

**Laurie:** Maybe a little may a little more assurance that they're, you know, interested in in.



(00:21:12 - 00:21:13)

**Stacey:** Mhmm.



(00:21:13 - 00:21:14)

**Laurie:** What's important to the patients.



(00:21:15 - 00:21:21)

**Stacey:** Got it. Lori, do you lack trust in the company currently?



(00:21:23 - 00:21:39)

**Laurie:** Not not in Genentech specifically, but I I think most people lack trust in big pharma in some way or the other. I mean, and and I don't know if it's lack trust, but, I mean, they're they're for profit business.



(00:21:39 - 00:21:40)

**Stacey:** Mhmm.



(00:21:40 - 00:21:58)

**Laurie:** Their their main, you know, their main goal is to make money for their shareholders. That's what companies do. But this would make me think that that they're actually thinking about the needs of the patient as well. And and I don't hate big pharma. I mean, I.



(00:21:58 - 00:21:59)

**Stacey:** Yep.



(00:21:58 - 00:21:59)

**Laurie:** Love these treatments.



(00:21:59 - 00:22:00)

**Stacey:** Mhmm.



(00:21:59 - 00:22:00)

**Laurie:** For SMA.



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

**Stacey:** Yeah.



(00:22:00 - 00:22:05)

**Laurie:** Don't get me wrong. But, obviously, they're they're there to make profit. That's their job.



(00:22:04 - 00:22:05)

**Stacey:** Yep.



(00:22:05 - 00:22:09)

**Laurie:** So you just have to balance the two in in your brain kind of.



(00:22:10 - 00:22:26)

**Stacey:** Got it. So based on reading these three messages, does it, I don't know, change your perspective on Genentech at all seeing this information?



(00:22:27 - 00:22:35)

**Laurie:** I mean, I don't have a bad view of Genentech. It just they produced a drug that just didn't work for me.



(00:22:35 - 00:22:36)

**Stacey:** Yep.



(00:22:35 - 00:22:43)

**Laurie:** I mean, I don't I I I love that my sister takes it. She's doing great. It work how the hell it can work for her and not.



(00:22:43 - 00:22:44)

**Stacey:** Right.



(00:22:43 - 00:22:44)

**Laurie:** Me when we're surprised?



(00:22:44 - 00:22:45)

**Stacey:** Mhmm.



(00:22:44 - 00:22:45)

**Laurie:** I don't understand.



(00:22:46 - 00:22:47)

**Stacey:** Right.



(00:22:46 - 00:22:50)

**Laurie:** But she's doing great on it, so I don't.



(00:22:50 - 00:22:50)

**Stacey:** Yeah.



(00:22:50 - 00:22:51)

**Laurie:** Have any feelings.



(00:22:50 - 00:22:51)

**Stacey:** Yeah.



(00:22:51 - 00:22:54)

**Laurie:** Towards Genentech. I'm glad it's helping my sister.



(00:22:54 - 00:22:55)

**Stacey:** Got it.



(00:22:54 - 00:22:55)

**Laurie:** So.



(00:22:57 - 00:23:04)

**Stacey:** I'd like to have you rank these messages from one to three just based on your preference.



(00:23:04 - 00:23:06)

**Laurie:** Number the first one is number one.



(00:23:06 - 00:23:07)

**Stacey:** Okay.



(00:23:12 - 00:23:15)

**Laurie:** And I probably in the order they're in. One,



(00:23:15 - 00:23:15)

**Stacey:** Okay.



(00:23:15 - 00:23:16)

**Laurie:** Two, three. Yeah.



(00:23:19 - 00:23:22)

**Stacey:** Let's talk a little bit more about the d then, the first one. Can you.



(00:23:22 - 00:23:23)

**Laurie:** Yep.



(00:23:22 - 00:23:27)

**Stacey:** Tell me more about why that you're preferring that statement overall?



(00:23:26 - 00:23:41)

**Laurie:** I think, like I said before, because it talks about collaborating with the SMA community, listening to the patient's needs, taking their feedback. So, obviously, they're they're actively getting information back from patients.



(00:23:41 - 00:23:41)

**Stacey:** Mhmm.



(00:23:41 - 00:23:47)

**Laurie:** That would make me feel more secure in a drug company that.



(00:23:46 - 00:23:47)

**Stacey:** Got it.



(00:23:47 - 00:23:50)

**Laurie:** The patient's being listened to and.



(00:23:50 - 00:23:50)

**Stacey:** And it.



(00:23:50 - 00:23:50)

**Laurie:** That.



(00:23:50 - 00:23:50)

**Stacey:** Goes.



(00:23:50 - 00:23:50)

**Laurie:** They.



(00:23:50 - 00:23:50)

**Stacey:** On.



(00:23:50 - 00:23:52)

**Laurie:** Can a drug based.



(00:23:52 - 00:23:53)

**Stacey:** Mhmm.



(00:23:52 - 00:23:55)

**Laurie:** On patient input.



(00:23:55 - 00:23:55)

**Stacey:** Mhmm.



(00:23:55 - 00:23:56)

**Laurie:** Or.



(00:23:55 - 00:23:56)

**Stacey:** Okay.



(00:23:56 - 00:23:57)

**Laurie:** A formulation of the drug.



(00:23:58 - 00:23:59)

**Stacey:** Got it.



(00:23:59 - 00:23:59)

**Laurie:** Yeah.



(00:24:02 - 00:24:09)

**Stacey:** Alright. Thank you. And why? Tell me your thoughts about that one.



(00:24:11 - 00:24:36)

**Laurie:** I like that it says that they have over five years of experience within the community. It just shows that they they're not brand new. Like, they've obviously, if they're still this drug's still being made, they're still helping people. It's working for people. I think that that's a good thing to lead with for some who's trying to decide on which drug to take, what therapy.



(00:24:36 - 00:24:36)

**Stacey:** Well,



(00:24:36 - 00:24:36)

**Laurie:** To.



(00:24:38 - 00:24:40)

**Stacey:** So you made me just think of something. I.



(00:24:40 - 00:24:41)

**Laurie:** Mhmm.



(00:24:40 - 00:24:47)

**Stacey:** Wanna be sure that as we talk about these, that you're coming just from your thoughts and feelings. In other words,



(00:24:47 - 00:24:48)

**Laurie:** Oh, absolutely.



(00:24:48 - 00:24:50)

**Stacey:** Worry how anyone else would react.



(00:24:49 - 00:24:50)

**Laurie:** Yep.



(00:24:50 - 00:24:50)

**Stacey:** To these,



(00:24:50 - 00:24:50)

**Laurie:** No.



(00:24:50 - 00:24:50)

**Stacey:** But.



(00:24:50 - 00:24:51)

**Laurie:** No.



(00:24:50 - 00:24:51)

**Stacey:** Okay.



(00:24:52 - 00:24:52)

**Laurie:** No.



(00:24:52 - 00:24:54)

**Stacey:** Okay. And so tell.



(00:24:54 - 00:24:55)

**Laurie:** If.



(00:24:54 - 00:24:55)

**Stacey:** Me more.



(00:24:55 - 00:24:55)

**Laurie:** If.



(00:24:55 - 00:24:55)

**Stacey:** About.



(00:24:55 - 00:25:00)

**Laurie:** If I weren't on a treatment and I was trying to decide which one, it would make me feel good.



(00:25:00 - 00:25:01)

**Stacey:** Well,



(00:25:00 - 00:25:01)

**Laurie:** That they'd.



(00:25:01 - 00:25:01)

**Stacey:** Got it.



(00:25:01 - 00:25:03)

**Laurie:** Had experience.



(00:25:01 - 00:25:08)

**Stacey:** Okay. Got it. I just don't want you to pretend. I want you to be who you are.



(00:25:08 - 00:25:08)

**Laurie:** Okay.



(00:25:08 - 00:25:12)

**Stacey:** In the situation you're in. You are on treatment. In fact, you've been on this drug before.



(00:25:12 - 00:25:13)

**Laurie:** I.



(00:25:12 - 00:25:13)

**Stacey:** So.



(00:25:13 - 00:25:13)

**Laurie:** Have.



(00:25:14 - 00:25:29)

**Stacey:** So hearing that, you know, has five years of experience in, you know, people with SMA, does that yeah. I mean, is that meaningful to you at this point in time?



(00:25:29 - 00:25:33)

**Laurie:** Yeah. I mean, it's it's meaningful. It's not gonna get me to switch back,



(00:25:33 - 00:25:33)

**Stacey:** Right. Right.



(00:25:33 - 00:25:34)

**Laurie:** But.



(00:25:33 - 00:25:35)

**Stacey:** Got it. Yeah.



(00:25:34 - 00:25:35)

**Laurie:** But it's new.



(00:25:35 - 00:25:35)

**Stacey:** Got.



(00:25:35 - 00:25:35)

**Laurie:** Yeah.



(00:25:35 - 00:25:36)

**Stacey:** It.



(00:25:35 - 00:25:38)

**Laurie:** It's a good thing it's a good thing to say. I mean,



(00:25:38 - 00:25:49)

**Stacey:** Mhmm. Okay. And as you said, it tells you that it's not brand new. Like, why why is that a good thing to say? What what do you like about hearing that?



(00:25:51 - 00:26:02)

**Laurie:** I think it it shows that it it's a trusted and proven therapy, that it's not I I don't think I would worry so much about taking it.



(00:26:02 - 00:26:02)

**Stacey:** Mhmm.



(00:26:02 - 00:26:05)

**Laurie:** Because I know it's it's proven, and it's been used,



(00:26:05 - 00:26:06)

**Stacey:** Yep.



(00:26:05 - 00:26:13)

**Laurie:** And it's safe. And it was scary taking SPINRAZA right off the bat when it first got approved. That.



(00:26:13 - 00:26:13)

**Stacey:** Mhmm.



(00:26:13 - 00:26:14)

**Laurie:** Was scary.



(00:26:14 - 00:26:14)

**Stacey:** Mhmm.



(00:26:15 - 00:26:16)

**Laurie:** You know? But.



(00:26:18 - 00:26:19)

**Stacey:** Got.



(00:26:19 - 00:26:19)

**Laurie:** I.



(00:26:19 - 00:26:19)

**Stacey:** It.



(00:26:19 - 00:26:23)

**Laurie:** Would've taken it with without the approval. I would've tried.



(00:26:23 - 00:26:24)

**Stacey:** Okay.



(00:26:23 - 00:26:23)

**Laurie:** Anything.



(00:26:25 - 00:26:37)

**Stacey:** Okay. And then in statement y, it is saying that it is the most chosen medicine. I'm gonna highlight that for.



(00:26:37 - 00:26:37)

**Laurie:** That.



(00:26:37 - 00:26:38)

**Stacey:** SMA.



(00:26:37 - 00:26:39)

**Laurie:** That makes sense to me. Yeah.



(00:26:39 - 00:26:40)

**Stacey:** Does it?



(00:26:40 - 00:26:41)

**Laurie:** Because.



(00:26:40 - 00:26:41)

**Stacey:** Tell.



(00:26:41 - 00:26:41)

**Laurie:** Of the.



(00:26:41 - 00:26:41)

**Stacey:** Me.



(00:26:41 - 00:26:42)

**Laurie:** Administration.



(00:26:42 - 00:26:44)

**Stacey:** Okay. Got it.



(00:26:44 - 00:26:48)

**Laurie:** I I would choose that over a spinal injection if.



(00:26:48 - 00:26:49)

**Stacey:** Yes.



(00:26:48 - 00:26:49)

**Laurie:** If.



(00:26:49 - 00:26:49)

**Stacey:** Okay.



(00:26:49 - 00:26:51)

**Laurie:** Yeah. I think anybody would.



(00:26:51 - 00:27:05)

**Stacey:** Right. Okay. I'm curious. Right now, it says most chosen. It could say most prescribed. I'm curious what is the more meaningful idea for you.



(00:27:05 - 00:27:05)

**Laurie:** I.



(00:27:05 - 00:27:05)

**Stacey:** Most.



(00:27:05 - 00:27:05)

**Laurie:** Think.



(00:27:05 - 00:27:06)

**Stacey:** Chosen?



(00:27:05 - 00:27:06)

**Laurie:** Chosen because it.



(00:27:06 - 00:27:07)

**Stacey:** Okay.



(00:27:06 - 00:27:09)

**Laurie:** Relates more to the patient than the doctor.



(00:27:10 - 00:27:11)

**Stacey:** Okay. Mhmm.



(00:27:11 - 00:27:19)

**Laurie:** It means you know, I'm sure you sit down with your doctor and discuss things, but chosen means, like, I chose that.



(00:27:19 - 00:27:19)

**Stacey:** Right.



(00:27:19 - 00:27:20)

**Laurie:** I'm.



(00:27:19 - 00:27:20)

**Stacey:** Got it.



(00:27:20 - 00:27:20)

**Laurie:** The.



(00:27:20 - 00:27:23)

**Stacey:** Okay. Got it.



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

**Laurie:** Trained.



(00:27:25 - 00:27:37)

**Stacey:** You know, I I have a land believe it or not, I have a landline still. And, yeah, unlike a phone, you can't silence it ahead of time. So.



(00:27:37 - 00:27:38)

**Laurie:** No. You can't. No.



(00:27:38 - 00:27:39)

**Stacey:** You'll wait outside or.



(00:27:39 - 00:27:39)

**Laurie:** Well,



(00:27:39 - 00:27:40)

**Stacey:** A cell.



(00:27:39 - 00:27:40)

**Laurie:** If.



(00:27:40 - 00:27:40)

**Stacey:** Phone.



(00:27:40 - 00:27:43)

**Laurie:** Mine rings, you're gonna hear the cantina music from Star Wars.



(00:27:43 - 00:27:47)

**Stacey:** Oh, well, did see your Star Wars blanket, so I love that. I would.



(00:27:47 - 00:27:48)

**Laurie:** Oh,



(00:27:47 - 00:27:49)

**Stacey:** Not have been surprised necessarily.



(00:27:49 - 00:27:52)

**Laurie:** Oh, we got to stop the cat from scratching the leather sofa.



(00:27:52 - 00:27:52)

**Stacey:** Yeah.



(00:27:52 - 00:27:53)

**Laurie:** Yeah. Yeah.



(00:27:55 - 00:28:04)

**Stacey:** And then k statement k took your third spot. Tell me why that actually, no. Forgive me. Before I I don't wanna go so quickly. Seeing.



(00:28:04 - 00:28:05)

**Laurie:** Mhmm.



(00:28:04 - 00:28:10)

**Stacey:** The twenty one thousand patients worldwide, curious just thoughts about that data point.



(00:28:11 - 00:28:21)

**Laurie:** I mean, it it seems like a lot of patients. I don't know how many patients there are worldwide, like, on treatment. So but that seems like a a lot of people.



(00:28:21 - 00:28:21)

**Stacey:** Mhmm.



(00:28:21 - 00:28:21)

**Laurie:** On.



(00:28:21 - 00:28:22)

**Stacey:** Mhmm.



(00:28:21 - 00:28:22)

**Laurie:** A first date.



(00:28:23 - 00:28:30)

**Stacey:** Yep. Got it. Okay. And then statement k, the that that got your third ranking.



(00:28:32 - 00:28:58)

**Laurie:** I think the thing that put me off right at the start was, the largest biotech in the world. Like, I don't care how big they are. Like, that doesn't mean anything to me. I I don't know. And it just might be me, but, like, I don't know. It's like saying some companies, like, we're the largest manufacturer of soda or whatever. Like, I don't care.



(00:28:58 - 00:28:59)

**Stacey:** Mhmm.



(00:28:58 - 00:28:59)

**Laurie:** Just be the best.



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

**Stacey:** Got it. Okay.



(00:29:01 - 00:29:05)

**Laurie:** Doesn't doesn't cut it for me. It might for some people, but.



(00:29:04 - 00:29:05)

**Stacey:** Mhmm.



(00:29:05 - 00:29:09)

**Laurie:** I just feel like that's like, oh, look at us. You know? Like, a bragging kind of, like,



(00:29:09 - 00:29:11)

**Stacey:** Yep. Yep. Okay.



(00:29:11 - 00:29:16)

**Laurie:** And I'm not impressed. But maybe I'm fussy.



(00:29:18 - 00:29:23)

**Stacey:** What else? Anything else in Kay that put it at the bottom?



(00:29:24 - 00:29:33)

**Laurie:** I mean, it's good that they say they're committed to helping people access the medicines they need, which makes me think that, you know, what it goes on to say about support programs.



(00:29:33 - 00:29:34)

**Stacey:** Mhmm.



(00:29:33 - 00:29:36)

**Laurie:** Because I was on the one when I started.



(00:29:37 - 00:29:37)

**Stacey:** Mhmm.



(00:29:38 - 00:29:43)

**Laurie:** I don't I think I paid, like, 5 to $10 a shipment,



(00:29:43 - 00:29:43)

**Stacey:** Okay.



(00:29:43 - 00:29:45)

**Laurie:** So it was I couldn't have afforded it otherwise.



(00:29:45 - 00:29:46)

**Stacey:** Right. Okay.



(00:29:46 - 00:29:47)

**Laurie:** Oh, that's.



(00:29:47 - 00:29:47)

**Stacey:** Got.



(00:29:47 - 00:29:47)

**Laurie:** Good.



(00:29:47 - 00:29:48)

**Stacey:** It. Okay.



(00:29:48 - 00:29:58)

**Laurie:** That's not a bad. That third one's not awful. It's just that largest biotech in the world. I'm not sure that's, like, the brag they think it is.



(00:29:59 - 00:29:59)

**Stacey:** Got it.



(00:29:59 - 00:30:03)

**Laurie:** I don't know. I think that's a better way to say something like.



(00:30:02 - 00:30:03)

**Stacey:** Okay.



(00:30:03 - 00:30:03)

**Laurie:** That.



(00:30:03 - 00:30:04)

**Stacey:** Well.



(00:30:03 - 00:30:04)

**Laurie:** Most.



(00:30:04 - 00:30:05)

**Stacey:** And that's.



(00:30:04 - 00:30:06)

**Laurie:** Or.



(00:30:05 - 00:30:18)

**Stacey:** That's exactly why we're testing these, so I really value that input. What about the whole leading the way with groundbreaking therapies and pioneering innovation? Like, what was your impression of that part?



(00:30:18 - 00:30:22)

**Laurie:** Yeah. Yeah. I mean, they're the only ones with an oral therapy,



(00:30:22 - 00:30:23)

**Stacey:** Mhmm.



(00:30:22 - 00:30:24)

**Laurie:** So that's very true. I.



(00:30:24 - 00:30:25)

**Stacey:** Yeah.



(00:30:24 - 00:30:25)

**Laurie:** Mean,



(00:30:25 - 00:30:25)

**Stacey:** Okay.



(00:30:26 - 00:30:28)

**Laurie:** But they're the only ones doing an oral therapy,



(00:30:28 - 00:30:28)

**Stacey:** Mhmm.



(00:30:28 - 00:30:28)

**Laurie:** So they're.



(00:30:28 - 00:30:29)

**Stacey:** Okay.



(00:30:28 - 00:30:30)

**Laurie:** Not really comparing to anyone but themselves.



(00:30:31 - 00:30:37)

**Stacey:** Got it. Okay. Let's do our next category.



(00:30:37 - 00:30:38)

**Laurie:** Alright.



(00:30:38 - 00:30:51)

**Stacey:** So as you well know, new treatment options are on the horizon, including the expanded indication for the gene therapy. It's actually anticipated to be up to 18 years old.



(00:30:51 - 00:30:51)

**Laurie:** Okay.



(00:30:51 - 00:31:08)

**Stacey:** And, so the introduction of new therapies may prompt patients to start a conversation with their doctor about switching. However, managing SMA is a lifelong journey, so it's important to consider how switching therapies might impact your insurance coverage and future coverage. So.



(00:31:08 - 00:31:09)

**Laurie:** Yeah.



(00:31:08 - 00:31:17)

**Stacey:** This set of messages is really looking to the future state, the future scenario where there will be additional options, including gene.



(00:31:17 - 00:31:18)

**Laurie:** Okay.



(00:31:17 - 00:31:21)

**Stacey:** Therapy for older children. So I'll go I'll let you have a look at this.



(00:31:44 - 00:31:45)

**Laurie:** Okay.



(00:31:46 - 00:31:49)

**Stacey:** What's your impression of this collection of messages?



(00:31:50 - 00:31:51)

**Laurie:** I think it's good information.



(00:31:52 - 00:31:52)

**Stacey:** Mhmm.



(00:31:53 - 00:31:59)

**Laurie:** And I'm I would hope that most doctors would be telling their patients all of this.



(00:31:59 - 00:31:59)

**Stacey:** Mhmm.



(00:32:00 - 00:32:12)

**Laurie:** Because gene therapy is extremely expensive. And I know that I know people who have have had that and then had a really hard time getting something like afterwards.



(00:32:15 - 00:32:15)

**Stacey:** Got it.



(00:32:16 - 00:32:23)

**Laurie:** I think last time I looked, gene therapy was, like, over 2,000,000. So it's a big ask.



(00:32:23 - 00:32:25)

**Stacey:** Mhmm. Yep. Okay.



(00:32:24 - 00:32:25)

**Laurie:** Yeah.



(00:32:26 - 00:32:31)

**Stacey:** So this this rings true then from based on conversations and things that you.



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

**Laurie:** Yes.



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

**Stacey:** Know about what's.



(00:32:32 - 00:32:33)

**Laurie:** Absolutely.



(00:32:32 - 00:32:33)

**Stacey:** Happening. Okay.



(00:32:33 - 00:32:34)

**Laurie:** I.



(00:32:33 - 00:32:34)

**Stacey:** Okay.



(00:32:34 - 00:32:40)

**Laurie:** Do know people who have managed both, who have have had the gene therapy for babies and or, you know, under twos, basically,



(00:32:40 - 00:32:41)

**Stacey:** Mhmm.



(00:32:41 - 00:32:45)

**Laurie:** When they were little and then still got approved for either SPINRAZA or EVRIZDA.



(00:32:45 - 00:32:46)

**Stacey:** Okay.



(00:32:45 - 00:32:46)

**Laurie:** After.



(00:32:47 - 00:32:49)

**Stacey:** Do you know how they manage that? Like, was.



(00:32:49 - 00:32:49)

**Laurie:** No.



(00:32:49 - 00:32:50)

**Stacey:** There something that.



(00:32:49 - 00:32:50)

**Laurie:** No.



(00:32:50 - 00:32:51)

**Stacey:** They yeah. K.



(00:32:51 - 00:32:53)

**Laurie:** I'm guessing good insurance.



(00:32:53 - 00:32:54)

**Stacey:** Yeah.



(00:32:54 - 00:32:55)

**Laurie:** You know?



(00:32:55 - 00:33:00)

**Stacey:** How would you rank these statements in terms of your preference?



(00:33:03 - 00:33:22)

**Laurie:** I feel like they, like, tell a story kind of. I wasn't really thinking of them as one as better than the other. I think important wise, the second one is to the point like, it's it doesn't meant words. Like, it's saying be careful.



(00:33:22 - 00:33:23)

**Stacey:** Okay.



(00:33:23 - 00:33:27)

**Laurie:** If you get this gene therapy, you might have trouble getting.



(00:33:27 - 00:33:27)

**Stacey:** And.



(00:33:27 - 00:33:28)

**Laurie:** Anything.



(00:33:27 - 00:33:30)

**Stacey:** That's okay that it's to the point and doesn't mince.



(00:33:30 - 00:33:30)

**Laurie:** Oh,



(00:33:30 - 00:33:30)

**Stacey:** Words?



(00:33:30 - 00:33:31)

**Laurie:** Absolutely. Yeah.



(00:33:31 - 00:33:31)

**Stacey:** Okay.



(00:33:31 - 00:33:42)

**Laurie:** I think it's it's make it as help navigating health insurance and this kind of stuff is so ridiculously and unnecessarily complicated as it is.



(00:33:42 - 00:33:43)

**Stacey:** Okay.



(00:33:43 - 00:33:47)

**Laurie:** I think most people would be genuinely pleased just to have something straight and to the point.



(00:33:47 - 00:33:48)

**Stacey:** Okay.



(00:33:48 - 00:33:49)

**Laurie:** Yeah.



(00:33:49 - 00:33:49)

**Stacey:** Alright.



(00:33:49 - 00:34:17)

**Laurie:** 100%. And maybe the last one would be number two because I think maybe people don't realize that such a large percentage of patients who get gene therapy still go on to need further treatment. A lot of people think, you know, gene therapy is a one and done, and it is, but that doesn't necessarily mean you won't need something different going forward.



(00:34:18 - 00:34:32)

**Stacey:** So what is it what are the like, what are you thinking? Like, seeing this average of forty four percent of patients still need a DMT, like, what, I don't know, impression or impact is it having for you to to see that?



(00:34:33 - 00:35:08)

**Laurie:** It I'm a little surprised. I didn't realize it was that high. I don't know. I don't know. I'm surprised. You know? I didn't I didn't realize that that higher percentage of patients still had another disease modifying treatment after gene therapy. And I it would make me wonder, is that because patients were closer to two when they started it? Because I believe it's more effective the earlier the treatment is received. I'd be curious to know,



(00:35:08 - 00:35:09)

**Stacey:** Got.



(00:35:09 - 00:35:09)

**Laurie:** But.



(00:35:09 - 00:35:09)

**Stacey:** It.



(00:35:09 - 00:35:15)

**Laurie:** That would be thought. But I would wonder if it was the older kids that were still having to go on other treatments.



(00:35:15 - 00:35:17)

**Stacey:** Okay. Got it.



(00:35:17 - 00:35:23)

**Laurie:** And that makes me think that if it's gonna be approved for kids up to 18, that number will probably go up.



(00:35:23 - 00:35:24)

**Stacey:** Okay.



(00:35:24 - 00:35:24)

**Laurie:** That.



(00:35:26 - 00:35:27)

**Stacey:** Lori,



(00:35:26 - 00:35:27)

**Laurie:** Be even.



(00:35:27 - 00:35:27)

**Stacey:** I'm.



(00:35:27 - 00:35:27)

**Laurie:** High.



(00:35:27 - 00:35:34)

**Stacey:** Gonna pause for one second and bear with me. I have an important note that's coming from the team that I just need to take a look at, so just bear with.



(00:35:34 - 00:35:34)

**Laurie:** Yeah.



(00:35:34 - 00:35:34)

**Stacey:** Me for.



(00:35:34 - 00:35:34)

**Laurie:** No.



(00:35:34 - 00:35:34)

**Stacey:** A.



(00:35:34 - 00:35:34)

**Laurie:** Problem.



(00:35:34 - 00:36:41)

**Stacey:** Moment. Alright. So let's we've had some version changes, and so let's see. What would be the best way to go here? Bear with me for a second, Laurie. Luke, how about if I just briefly show the next two sections for you to take a quick look at, and you can tell me if this looks to be the right, okay. I don't I don't think I have another version to go to. Okay. And then here's the last section. Okay. Good. Alright. Okay. Great. So, Luke, I'm gonna keep going then. Is that okay? Okay. Perfect. Alright. We're gonna keep going. Thank you, Laurie. I.



(00:36:40 - 00:36:41)

**Laurie:** Mhmm.



(00:36:41 - 00:36:42)

**Stacey:** I appreciate that.



(00:36:42 - 00:36:45)

**Laurie:** That's why I gave you the message check the email that came in.



(00:36:45 - 00:37:05)

**Stacey:** Oh, good. Okay. Good. So let's see. There's a question. You know, I'm gonna there's a again, I'm just gonna be transparent. There's a question that we added relating to this. I don't see it in this guide, but I'm gonna go ahead and ask it anyway.



(00:37:04 - 00:37:05)

**Laurie:** Okay.



(00:37:05 - 00:37:09)

**Stacey:** Just in case, they'll let me know if I shouldn't have asked it, but it won't hurt anything.



(00:37:11 - 00:37:11)

**Laurie:** I.



(00:37:11 - 00:37:12)

**Stacey:** Here,



(00:37:11 - 00:37:12)

**Laurie:** Won't have.



(00:37:12 - 00:37:12)

**Stacey:** It says.



(00:37:12 - 00:37:12)

**Laurie:** One.



(00:37:13 - 00:37:30)

**Stacey:** Right. So you yeah. You will know the difference. It says an average of forty four percent of patients still need a disease modifying therapy. We could have stated it as anywhere from twelve to seventy percent. So instead of giving an average, we could have given a range from twelve to seventy percent.



(00:37:30 - 00:37:32)

**Laurie:** I'd I'd give the average.



(00:37:32 - 00:37:34)

**Stacey:** Okay. Tell me why the average is.



(00:37:34 - 00:37:36)

**Laurie:** I don't wanna hear seventy percent.



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

**Stacey:** Okay. Got.



(00:37:37 - 00:37:38)

**Laurie:** Yeah.



(00:37:37 - 00:37:37)

**Stacey:** It.



(00:37:38 - 00:37:42)

**Laurie:** To lower the number I mean, I know you say twelve to 70, but.



(00:37:42 - 00:37:42)

**Stacey:** Mhmm.



(00:37:42 - 00:37:43)

**Laurie:** My brain is focused on the 70.



(00:37:44 - 00:37:45)

**Stacey:** Okay. Got it.



(00:37:45 - 00:37:45)

**Laurie:** 40.



(00:37:45 - 00:37:45)

**Stacey:** Okay.



(00:37:45 - 00:37:47)

**Laurie:** Four sounds better.



(00:37:47 - 00:37:50)

**Stacey:** Yes. Okay. Alright. Understood. Thank you.



(00:37:50 - 00:37:51)

**Laurie:** Mhmm.



(00:37:51 - 00:37:56)

**Stacey:** Alright. Let's finish ranking these. What would you put third? What would you put fourth?



(00:37:56 - 00:37:57)

**Laurie:** The s to l.



(00:37:58 - 00:38:03)

**Stacey:** Because I'll go ahead. Okay. Alright.



(00:38:03 - 00:38:03)

**Laurie:** And I.



(00:38:03 - 00:38:04)

**Stacey:** So.



(00:38:03 - 00:38:09)

**Laurie:** Think it's it's basically it's reassuring you that the I forgot they were called pals.



(00:38:09 - 00:38:09)

**Stacey:** Mhmm.



(00:38:10 - 00:38:17)

**Laurie:** That they have the pals that are help that are there to help you if you have any issues with getting back on a VRSDA afterwards.



(00:38:16 - 00:38:18)

**Stacey:** Mhmm. Yep.



(00:38:17 - 00:38:18)

**Laurie:** So that's reassuring.



(00:38:19 - 00:38:32)

**Stacey:** Got it. Actually, okay. And then w came in fourth. Tell me why that is the least preferable.



(00:38:32 - 00:38:32)

**Laurie:** I.



(00:38:32 - 00:38:33)

**Stacey:** Of these.



(00:38:32 - 00:38:34)

**Laurie:** Don't think it gave a lot of information.



(00:38:35 - 00:38:35)

**Stacey:** Okay.



(00:38:35 - 00:38:44)

**Laurie:** It seems very, I'm trying to think what the word is. I don't I can it's a little confusing.



(00:38:46 - 00:38:47)

**Stacey:** Mhmm. Okay.



(00:38:47 - 00:38:49)

**Laurie:** It's really not telling you much.



(00:38:50 - 00:38:57)

**Stacey:** Got it. Okay. Okay. Thank you.



(00:38:57 - 00:38:58)

**Laurie:** Mhmm.



(00:39:00 - 00:39:23)

**Stacey:** Let's Okay. Yeah. I will ask one more question before I shift gears. So based on this you know, seeing these messages, would this kind of information in any way impact your willingness, your desire to want to switch therapies?



(00:39:26 - 00:39:31)

**Laurie:** I don't know that it would it would sorry. Can I ask that again one more time?



(00:39:32 - 00:39:42)

**Stacey:** Yes. Would exposure to this information, learning this information on this page, would it impact your willingness and your desire to switch therapies in the future?



(00:39:43 - 00:40:09)

**Laurie:** I don't know that it would impact my desire to switch therapies. I think it would give me a little more assurance that if I want obviously, I'm too old. But if I wanted to try the gene therapy, that there are there are things out there to help me get back on if I find that I need to in future. And by.



(00:40:09 - 00:40:09)

**Stacey:** Okay.



(00:40:09 - 00:40:12)

**Laurie:** The looks of it, almost half the people do. So,



(00:40:12 - 00:40:13)

**Stacey:** Mhmm. Okay.



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

**Laurie:** Yeah,



(00:40:15 - 00:40:15)

**Stacey:** Got it.



(00:40:15 - 00:40:15)

**Laurie:** It.



(00:40:15 - 00:40:15)

**Stacey:** Thank.



(00:40:15 - 00:40:16)

**Laurie:** Would.



(00:40:15 - 00:40:16)

**Stacey:** You.



(00:40:16 - 00:40:18)

**Laurie:** Reassure me that there's help if I needed.



(00:40:17 - 00:40:18)

**Stacey:** Okay.



(00:40:18 - 00:40:18)

**Laurie:** It.



(00:40:21 - 00:40:31)

**Stacey:** Alright. So this section pertains to the moment you and your doctor have made the decision to start treatment. Think about that moment and the processes that you've had to go through.



(00:40:32 - 00:40:33)

**Laurie:** Okay.



(00:40:33 - 00:40:34)

**Stacey:** As you consider these.



(00:40:34 - 00:40:58)

**Laurie:** Okay. Okay.



(00:40:59 - 00:40:59)

**Stacey:** Okay.



(00:41:01 - 00:41:01)

**Laurie:** Yep.



(00:41:01 - 00:41:03)

**Stacey:** What is your reaction to this collection?



(00:41:06 - 00:41:13)

**Laurie:** Again, a decent a good amount of information. The bottom one is I like the best,



(00:41:14 - 00:41:15)

**Stacey:** K.



(00:41:16 - 00:41:29)

**Laurie:** Because just the fact that it starts out with living with SMA can be a lot to manage. Like, it makes me feel heard. You know? Like, that peep they understand that,



(00:41:28 - 00:41:29)

**Stacey:** Okay.



(00:41:29 - 00:41:35)

**Laurie:** You know, this is not an easy road, but it just feels like kind maybe.



(00:41:36 - 00:41:36)

**Stacey:** Okay.



(00:41:36 - 00:41:46)

**Laurie:** Like, they're they're they understand that how hard this is. And I did it I don't know. I was surprised to see it there, but, like, in a good way.



(00:41:47 - 00:41:52)

**Stacey:** Okay. And can you say more about being surprised to see it there?



(00:41:52 - 00:41:57)

**Laurie:** I guess I don't maybe wouldn't normally it felt personal, kind of.



(00:41:57 - 00:41:58)

**Stacey:** Okay.



(00:41:58 - 00:41:59)

**Laurie:** I.



(00:41:59 - 00:41:59)

**Stacey:** Mhmm.



(00:41:59 - 00:42:04)

**Laurie:** Felt like it related to me. Like, they understand kind of.



(00:42:04 - 00:42:05)

**Stacey:** Got it.



(00:42:05 - 00:42:07)

**Laurie:** Maybe sympathize and and.



(00:42:07 - 00:42:16)

**Stacey:** Mhmm. And does that give you any particular thought or impression about Genentech or first.



(00:42:16 - 00:42:16)

**Laurie:** I mean,



(00:42:16 - 00:42:17)

**Stacey:** Rate?



(00:42:16 - 00:42:17)

**Laurie:** It would.



(00:42:17 - 00:42:17)

**Stacey:** Like.



(00:42:17 - 00:42:19)

**Laurie:** Yeah. It would my.



(00:42:19 - 00:42:20)

**Stacey:** Yeah.



(00:42:20 - 00:42:26)

**Laurie:** Again, not that I have a bad impression, but it it it's just reassuring, and it and it.



(00:42:25 - 00:42:26)

**Stacey:** Okay.



(00:42:26 - 00:42:31)

**Laurie:** It feels it feels like something they didn't have to do, but it feels nice that they did it kind.



(00:42:31 - 00:42:32)

**Stacey:** Okay.



(00:42:31 - 00:42:31)

**Laurie:** Of.



(00:42:32 - 00:42:32)

**Stacey:** Understood.



(00:42:32 - 00:42:36)

**Laurie:** Unnecessary, but but nice to see.



(00:42:36 - 00:42:37)

**Stacey:** Got it.



(00:42:38 - 00:43:04)

**Laurie:** I think a lot of times, most people with SMA don't people who don't have SMA, like, you cannot understand, like, how how much it is. Like, there's I'm people laugh at me about how, like, I overthink everything, but I have to. Like, I have to plan for every possible thing that can go wrong because stuff goes wrong all the time.



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

**Stacey:** Right.



(00:43:04 - 00:43:16)

**Laurie:** And that meant I just got was we're on step three of getting my wheelchair fixed. So to not have my wheelchair and to be in my crappy eight year old one that isn't as easy to transfer from,



(00:43:16 - 00:43:17)

**Stacey:** Mhmm.



(00:43:17 - 00:43:19)

**Laurie:** The battery doesn't last as long. It's.



(00:43:19 - 00:43:19)

**Stacey:** Mhmm.



(00:43:19 - 00:43:22)

**Laurie:** Super uncomfortable. So it's.



(00:43:22 - 00:43:23)

**Stacey:** Got it.



(00:43:22 - 00:43:29)

**Laurie:** Just there's always something you've always got a plan for every possible outcome.



(00:43:29 - 00:43:30)

**Stacey:** Got it.



(00:43:29 - 00:43:32)

**Laurie:** Absolutely exhausting.



(00:43:33 - 00:43:42)

**Stacey:** I knew at the beginning of our conversation that we had barely tipped the iceberg not even tipped the iceberg of what we could have talked about. So thank you for giving me some additional.



(00:43:43 - 00:43:43)

**Laurie:** Sure.



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

**Stacey:** Insight there.



(00:43:44 - 00:43:45)

**Laurie:** Sure.



(00:43:45 - 00:43:51)

**Stacey:** Yeah. We we could I we could fill the hour and plus there, but I but.



(00:43:51 - 00:43:52)

**Laurie:** Yeah.



(00:43:51 - 00:43:52)

**Stacey:** I appreciate.



(00:43:52 - 00:43:53)

**Laurie:** Yeah.



(00:43:53 - 00:43:55)

**Stacey:** I appreciate the the insight.



(00:43:54 - 00:43:55)

**Laurie:** Yeah.



(00:43:55 - 00:44:01)

**Stacey:** That you're giving me. Anything else about q that had you rank it first?



(00:44:02 - 00:44:13)

**Laurie:** Just the fact that they talk about how the PALS can assist with, like, all aspects of the RISD experience. So it makes you feel like you're not you're not alone. Like,



(00:44:13 - 00:44:13)

**Stacey:** Mhmm.



(00:44:13 - 00:44:14)

**Laurie:** There are people that help you on this journey.



(00:44:15 - 00:44:16)

**Stacey:** Okay.



(00:44:15 - 00:44:19)

**Laurie:** And I like that it says all aspects, like,



(00:44:18 - 00:44:19)

**Stacey:** Got it.



(00:44:19 - 00:44:21)

**Laurie:** All access aspect.



(00:44:21 - 00:44:21)

**Stacey:** Got.



(00:44:21 - 00:44:21)

**Laurie:** It was.



(00:44:21 - 00:44:22)

**Stacey:** It.



(00:44:21 - 00:44:25)

**Laurie:** All access. I don't know. Nieces have access in there, but,



(00:44:25 - 00:44:26)

**Stacey:** Mhmm.



(00:44:25 - 00:44:28)

**Laurie:** Like, all aspects of your RISD experience.



(00:44:29 - 00:44:29)

**Stacey:** Okay.



(00:44:29 - 00:44:32)

**Laurie:** Sound I wouldn't have access in there, but, you know,



(00:44:32 - 00:44:33)

**Stacey:** Got it. Well,



(00:44:33 - 00:44:33)

**Laurie:** I.



(00:44:33 - 00:44:34)

**Stacey:** Yes.



(00:44:33 - 00:44:34)

**Laurie:** Don't direct.



(00:44:34 - 00:44:34)

**Stacey:** Yeah.



(00:44:34 - 00:44:35)

**Laurie:** You for a living. So,



(00:44:36 - 00:44:45)

**Stacey:** Yeah. No. Understood. Yeah. The focus of this particular communication is access, but I get I get where you're coming from with that.



(00:44:45 - 00:44:45)

**Laurie:** Yeah.



(00:44:45 - 00:44:48)

**Stacey:** Okay. What would you rank?



(00:44:48 - 00:44:48)

**Laurie:** And the.



(00:44:48 - 00:44:49)

**Stacey:** Number.



(00:44:48 - 00:44:49)

**Laurie:** Fact that.



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

**Stacey:** Two.



(00:44:49 - 00:44:50)

**Laurie:** It's personalized support.



(00:44:50 - 00:44:50)

**Stacey:** Oh,



(00:44:50 - 00:44:51)

**Laurie:** Also.



(00:44:50 - 00:44:52)

**Stacey:** Got it. Okay. Thank you.



(00:44:52 - 00:44:57)

**Laurie:** Do you I that would make me think, you know, there's one person I'm gonna get to speak to all the time who's.



(00:44:57 - 00:44:58)

**Stacey:** Okay.



(00:44:57 - 00:44:59)

**Laurie:** Gonna be my liaison, who's gonna help me,



(00:44:59 - 00:45:00)

**Stacey:** Got.



(00:45:00 - 00:45:00)

**Laurie:** Which is.



(00:45:00 - 00:45:00)

**Stacey:** It.



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

**Laurie:** Nice. It's nice to have, like, a continuity to have the same person all the time. I think that's helpful.



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

**Stacey:** Okay.



(00:45:13 - 00:45:21)

**Laurie:** I'm trying to think best the second one. Probably the second one would be number two.



(00:45:22 - 00:45:22)

**Stacey:** Mhmm.



(00:45:24 - 00:45:25)

**Laurie:** V. No.



(00:45:25 - 00:45:31)

**Stacey:** Oh, forgive me. Yes. You said it, and I processed it incorrectly. Thank you. Okay.



(00:45:33 - 00:45:33)

**Laurie:** I think.



(00:45:33 - 00:45:33)

**Stacey:** And.



(00:45:33 - 00:45:54)

**Laurie:** Just the fact that it talks about understanding insurance coverage because it's insurance is so hard to understand. It and I still I mean, I lived in England for fifteen years, and, you know, you didn't pay for anything over there because it was National Health Service. So had I known what it was like here, I don't think I would have moved back to The States. I think I would have stayed in England.



(00:45:55 - 00:45:56)

**Stacey:** Okay.



(00:45:57 - 00:46:04)

**Laurie:** Because the amount of money we pay every month for health insurances should be criminal. So.



(00:46:04 - 00:46:04)

**Stacey:** Yeah.



(00:46:05 - 00:46:06)

**Laurie:** I definitely.



(00:46:06 - 00:46:06)

**Stacey:** Wow.



(00:46:06 - 00:46:06)

**Laurie:** Would have.



(00:46:06 - 00:46:06)

**Stacey:** Thank.



(00:46:06 - 00:46:06)

**Laurie:** Stayed.



(00:46:06 - 00:46:07)

**Stacey:** You.



(00:46:06 - 00:46:08)

**Laurie:** There and raised.



(00:46:07 - 00:46:08)

**Stacey:** Okay.



(00:46:08 - 00:46:10)

**Laurie:** My family in Europe, not in America.



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

**Stacey:** Got it. Okay.



(00:46:12 - 00:46:17)

**Laurie:** But I'm glad I didn't know in a way because my parents are here and my sister. And so.



(00:46:16 - 00:46:22)

**Stacey:** Right. And then tell me about x, about.



(00:46:22 - 00:46:22)

**Laurie:** I.



(00:46:22 - 00:46:23)

**Stacey:** That being your third ranked.



(00:46:30 - 00:46:37)

**Laurie:** Think probably I mean, it's it's just being honest, but I think the fact that it talks about denials are common,



(00:46:37 - 00:46:38)

**Stacey:** Mhmm.



(00:46:37 - 00:46:40)

**Laurie:** It just has such a negative connotation.



(00:46:39 - 00:46:40)

**Stacey:** Mhmm. Okay.



(00:46:40 - 00:46:55)

**Laurie:** That that probably put me off, and that's probably why I put it as number three. I'm sure that's information that's important to get to people, but you know? And then it says they can always be appealed. So that that's of the positive side.



(00:46:55 - 00:47:01)

**Stacey:** Yeah. Okay. What did you think about the four out of five appeals are successful?



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

**Laurie:** I thought it would have been higher.



(00:47:04 - 00:47:04)

**Stacey:** Okay.



(00:47:05 - 00:47:10)

**Laurie:** So that makes me a little sad that twenty percent of people are.



(00:47:09 - 00:47:10)

**Stacey:** Right.



(00:47:10 - 00:47:13)

**Laurie:** Being denied a medicine that their doctors say they need,



(00:47:12 - 00:47:14)

**Stacey:** Okay. Okay.



(00:47:14 - 00:47:18)

**Laurie:** But that the American way, unfortunately. So.



(00:47:19 - 00:47:30)

**Stacey:** Yeah. Alright. Let's take a look at our final category here.



(00:47:35 - 00:47:47)

**Laurie:** K. Okay.



(00:47:49 - 00:47:54)

**Stacey:** What do you think about this collection overall? How are they landing for you?



(00:47:54 - 00:47:57)

**Laurie:** The last one, think, would be my favorite,



(00:47:57 - 00:47:58)

**Stacey:** Mhmm.



(00:47:59 - 00:48:04)

**Laurie:** Because I like that it says it's even including people who are uninsured.



(00:48:05 - 00:48:05)

**Stacey:** Okay.



(00:48:05 - 00:48:09)

**Laurie:** And letting you know that there's a patient foundation to help even if you don't have insurance,



(00:48:10 - 00:48:10)

**Stacey:** Got it.



(00:48:11 - 00:48:14)

**Laurie:** Which because there's a lot of uninsured people in.



(00:48:14 - 00:48:14)

**Stacey:** Had.



(00:48:14 - 00:48:14)

**Laurie:** This country.



(00:48:14 - 00:48:17)

**Stacey:** You heard of the Genentech Patient Foundation previously?



(00:48:18 - 00:48:34)

**Laurie:** I don't know that I I may have, but we've had insurance, so it wouldn't have applied to me. So I don't recall specifically. But that that's you know, that that's a nice thing. And that's that's what the drug company should do.



(00:48:34 - 00:48:35)

**Stacey:** Mhmm.



(00:48:34 - 00:48:35)

**Laurie:** I mean, that.



(00:48:35 - 00:48:35)

**Stacey:** Okay.



(00:48:35 - 00:48:46)

**Laurie:** That's what they should do. That's you know? Whether they can continue to keep doing it at the levels they're doing it at in the next year or two, I'll be curious to see.



(00:48:46 - 00:48:50)

**Stacey:** How so? Tell me more what you're think like, what you're thinking.



(00:48:49 - 00:48:50)

**Laurie:** But.



(00:48:50 - 00:48:50)

**Stacey:** About.



(00:48:50 - 00:48:50)

**Laurie:** I.



(00:48:50 - 00:48:50)

**Stacey:** Or.



(00:48:50 - 00:48:50)

**Laurie:** Think.



(00:48:50 - 00:48:51)

**Stacey:** Referring.



(00:48:50 - 00:48:51)

**Laurie:** That.



(00:48:51 - 00:48:51)

**Stacey:** To.



(00:48:51 - 00:49:00)

**Laurie:** If the subsidies aren't extended for the people on the ACA, then there's gonna be millions and millions of people who are losing their health insurance, which is.



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

**Stacey:** Got.



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

**Laurie:** Gonna.



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

**Stacey:** It.



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

**Laurie:** Be a real issue. I'm we're lucky. You know, my husband has a good job, touch wood. We get, I'm told, really good insurance, but it's really expensive through.



(00:49:12 - 00:49:13)

**Stacey:** Right.



(00:49:12 - 00:49:13)

**Laurie:** His company.



(00:49:13 - 00:49:14)

**Stacey:** Right.



(00:49:14 - 00:49:16)

**Laurie:** So it's not gonna affect me, hopefully, but I.



(00:49:16 - 00:49:17)

**Stacey:** Mhmm.



(00:49:17 - 00:49:18)

**Laurie:** We could see our premiums go up.



(00:49:19 - 00:49:20)

**Stacey:** Okay.



(00:49:19 - 00:49:21)

**Laurie:** And they're all crazy high.



(00:49:21 - 00:49:22)

**Stacey:** Right.



(00:49:21 - 00:49:22)

**Laurie:** So.



(00:49:22 - 00:49:23)

**Stacey:** Okay. Got it.



(00:49:24 - 00:49:27)

**Laurie:** But I, you know, I worry about the people who don't who can't afford insurance, who.



(00:49:27 - 00:49:28)

**Stacey:** Mhmm.



(00:49:27 - 00:49:28)

**Laurie:** Don't have insurance.



(00:49:33 - 00:49:34)

**Stacey:** What would you rank second and third?



(00:49:35 - 00:49:49)

**Laurie:** I would say going up again. The middle one's number two. Because I like that it talks about improving access and options for patient assistance, which.



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

**Stacey:** Okay.



(00:49:49 - 00:49:55)

**Laurie:** Kind of reminds me of f, the bottom one. It's a similar message just written differently.



(00:49:58 - 00:50:06)

**Stacey:** What about that phrasing? We've worked to minimize insurance bottlenecks and support patient and provider choice. Just curious what you think about that.



(00:50:08 - 00:50:11)

**Laurie:** I mean, I think it the insurance bottlenecks resonates, I'm sure.



(00:50:11 - 00:50:12)

**Stacey:** Yeah.



(00:50:12 - 00:50:23)

**Laurie:** Because people who either parents with children with SMA or adults, I mean, certainly understand the minefield that can be, you know, health insurance companies and.



(00:50:23 - 00:50:23)

**Stacey:** Right.



(00:50:23 - 00:50:24)

**Laurie:** Getting things approved.



(00:50:24 - 00:50:25)

**Stacey:** Okay.



(00:50:25 - 00:50:30)

**Laurie:** So I think that would be reassuring to people to see, or that would be reassuring to me to see.



(00:50:30 - 00:50:32)

**Stacey:** Okay. Tell me about r.



(00:50:38 - 00:50:45)

**Laurie:** I mean, it kinda says what the other ones say. It's just maybe with a little less information and finesse.



(00:50:45 - 00:50:48)

**Stacey:** Tell me about it being less less finesse.



(00:50:50 - 00:50:57)

**Laurie:** And this is just picky on my part. I don't like sentences that start with numbers. I don't know why.



(00:50:58 - 00:51:01)

**Stacey:** No. I I yeah. No. I I hear you on that.



(00:51:01 - 00:51:02)

**Laurie:** It's just weird.



(00:51:03 - 00:51:04)

**Stacey:** The.



(00:51:03 - 00:51:04)

**Laurie:** It could say.



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

**Stacey:** And.



(00:51:04 - 00:51:06)

**Laurie:** Up to 90%, or.



(00:51:06 - 00:51:06)

**Stacey:** Okay.



(00:51:06 - 00:51:09)

**Laurie:** There could be a. It just I don't know.



(00:51:09 - 00:51:10)

**Stacey:** No.



(00:51:10 - 00:51:10)

**Laurie:** I'm sure.



(00:51:10 - 00:51:10)

**Stacey:** I.



(00:51:10 - 00:51:10)

**Laurie:** It's.



(00:51:10 - 00:51:10)

**Stacey:** I.



(00:51:10 - 00:51:13)

**Laurie:** English, but I just don't like sentences that start with a number.



(00:51:13 - 00:51:24)

**Stacey:** Yeah. And, yeah, I'm sure the proper way would be to do it otherwise. Oh, let me ask you this. Given that these are meant these are such, like, rough drafts,



(00:51:24 - 00:51:25)

**Laurie:** Yep.



(00:51:24 - 00:51:36)

**Stacey:** Is there anything about the content that had you place it third? Because of, you know, like, smoothing out the sentences is an easy fix. So I'm curious.



(00:51:35 - 00:51:58)

**Laurie:** I think yeah. I think in the first one, the bottom ones talk about, like, improving access and support for uninsured and our commitment extends to everyone. And the first one kinda just says we have resources to help ensure that you have access to the treatment. But that kind of to me, it feels like it's laying it on me. Like,



(00:51:57 - 00:51:58)

**Stacey:** Mhmm.



(00:51:58 - 00:52:03)

**Laurie:** We're gonna give you the resources to sort it out. Whereas the other one, more like, we're going to help you.



(00:52:03 - 00:52:09)

**Stacey:** Got it. Okay. Got it. What do you think about the 90%?



(00:52:13 - 00:52:18)

**Laurie:** I don't I don't know. Like, I don't know whether I would expect that to be higher or lower. Or.



(00:52:20 - 00:52:20)

**Stacey:** Okay.



(00:52:21 - 00:52:29)

**Laurie:** I mean, I would have thought anybody with SMA should be covered for any drug their doctor says that they need.



(00:52:29 - 00:52:30)

**Stacey:** Okay.



(00:52:30 - 00:52:32)

**Laurie:** That's not the way it goes. So.



(00:52:32 - 00:52:33)

**Stacey:** Right.



(00:52:32 - 00:52:36)

**Laurie:** Maybe I honestly don't know. I don't know what I think about that.



(00:52:37 - 00:52:49)

**Stacey:** Alright. Scale of one to seven, how strong or not strong is that statistic? One would be that is not at all strong, 90%, and seven.



(00:52:49 - 00:52:49)

**Laurie:** Strong.



(00:52:49 - 00:52:49)

**Stacey:** Would.



(00:52:49 - 00:52:50)

**Laurie:** In.



(00:52:49 - 00:52:50)

**Stacey:** Be,



(00:52:50 - 00:52:51)

**Laurie:** What in what way?



(00:52:52 - 00:53:08)

**Stacey:** In in terms of a statistic, to say when you hear 90% of insured people have coverage for FRISD, how strong does that 90% statistic feel to you? One and it's purposely left for interpretation, but,



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

**Laurie:** Okay.



(00:53:09 - 00:53:15)

**Stacey:** You know, one is it's not strong at all. 10 is it's extremely alright. Yes. Excuse me. Seven is it's extremely strong.



(00:53:16 - 00:53:17)

**Laurie:** Then I would probably say six.



(00:53:17 - 00:53:19)

**Stacey:** Mhmm. Okay.



(00:53:20 - 00:53:22)

**Laurie:** I mean, it's a high number. It's a high percentage.



(00:53:22 - 00:53:23)

**Stacey:** Yeah. Okay.



(00:53:22 - 00:53:23)

**Laurie:** So.



(00:53:25 - 00:53:35)

**Stacey:** What if it was 80% or 70 or 60? Like, at what point would you say, okay. That's not a strong number anymore.



(00:53:39 - 00:53:40)

**Laurie:** Probably 70.



(00:53:40 - 00:53:45)

**Stacey:** Mhmm. Okay. Why 70?



(00:53:49 - 00:53:51)

**Laurie:** Because it should be higher than that. Like,



(00:53:51 - 00:53:51)

**Stacey:** Mhmm.



(00:53:51 - 00:53:59)

**Laurie:** That's not good that if 30% of people are being you know, don't even have it covered,



(00:53:59 - 00:54:00)

**Stacey:** Yeah. Got.



(00:54:00 - 00:54:00)

**Laurie:** That.



(00:54:00 - 00:54:00)

**Stacey:** It.



(00:54:00 - 00:54:03)

**Laurie:** That's high a number of people not getting what they.



(00:54:03 - 00:54:04)

**Stacey:** Mhmm.



(00:54:03 - 00:54:03)

**Laurie:** Need.



(00:54:05 - 00:54:23)

**Stacey:** Okay. Right now, says insured people. What if it said commercially insured people? What does that phrase commercially insured mean to you?



(00:54:23 - 00:54:45)

**Laurie:** People like me. I assume commercially to me means, people who get and I might be wrong, but people who get their insurance through their employer or who purchase insurance through the ACA, that would be I don't know if the ACA includes commercially insured. I would think it would, but I don't know for certain.



(00:54:45 - 00:54:51)

**Stacey:** Okay. Thank you. Here is.



(00:54:51 - 00:54:51)

**Laurie:** Oh,



(00:54:51 - 00:54:52)

**Stacey:** The.



(00:54:51 - 00:54:52)

**Laurie:** Those are.



(00:54:52 - 00:54:52)

**Stacey:** Full.



(00:54:52 - 00:54:53)

**Laurie:** Tiny.



(00:54:52 - 00:54:56)

**Stacey:** List of messages that we just looked at. Let me go a little bit larger.



(00:54:56 - 00:54:59)

**Laurie:** Please. My reading glasses can only do so much.



(00:55:01 - 00:55:01)

**Stacey:** It.



(00:55:01 - 00:55:01)

**Laurie:** Okay.



(00:55:01 - 00:55:02)

**Stacey:** Cuts off.



(00:55:01 - 00:55:02)

**Laurie:** That's.



(00:55:02 - 00:55:03)

**Stacey:** Just the very last Everest.



(00:55:03 - 00:55:03)

**Laurie:** That's okay.



(00:55:03 - 00:55:05)

**Stacey:** Word, but I think that's fair.



(00:55:05 - 00:55:05)

**Laurie:** Yeah.



(00:55:05 - 00:55:21)

**Stacey:** Enough. Alright. So could you select the statements, the messages that, in your opinion, create just the most compelling story regarding access to Everesty.



(00:55:22 - 00:55:24)

**Laurie:** How many am I.



(00:55:24 - 00:55:24)

**Stacey:** You.



(00:55:24 - 00:55:25)

**Laurie:** Looking?



(00:55:24 - 00:55:38)

**Stacey:** Are not limited. You can choose as few or as many as you'd like. You do you can include one or more from every category, or you can omit one or more categories altogether. You have free rein.



(00:55:39 - 00:55:40)

**Laurie:** Okay. Well, definitely d.



(00:55:41 - 00:55:42)

**Stacey:** LD?



(00:55:42 - 00:55:43)

**Laurie:** First one. Yep.



(00:55:43 - 00:55:43)

**Stacey:** Yep.



(00:55:43 - 00:55:45)

**Laurie:** N l y.



(00:55:45 - 00:55:45)

**Stacey:** K.



(00:55:47 - 00:56:00)

**Laurie:** Not L K. SL.



(00:56:01 - 00:56:02)

**Stacey:** K.



(00:56:16 - 00:56:37)

**Laurie:** HV. HQ. Headquarters. And CP and CF.



(00:56:38 - 00:56:43)

**Stacey:** Okay. What order would you feel.



(00:56:43 - 00:56:47)

**Laurie:** Well,



(00:56:43 - 00:56:45)

**Stacey:** Would be the most compelling?



(00:56:47 - 00:56:49)

**Laurie:** I like LD a lot.



(00:56:51 - 00:57:16)

**Stacey:** So start out. That would be the first like, if you were telling the story, you would start with LD. Oh, I forget. Not this. So not ranking them per se, but just, like, the order like, if, like, if we were to weave those statements together into the story, which one should they start with? And, like, you know, like, how how should be the progression of combining these ideas?



(00:57:18 - 00:57:26)

**Laurie:** I would say if you want to appeal to people straight away, then you would start with something like HQ.



(00:57:26 - 00:57:28)

**Stacey:** Okay. And that would so.



(00:57:28 - 00:57:29)

**Laurie:** Yeah.



(00:57:28 - 00:57:31)

**Stacey:** If we're if we're appealing to you, okay, start with HQ.



(00:57:31 - 00:57:32)

**Laurie:** Because yes. To.



(00:57:32 - 00:57:32)

**Stacey:** K.



(00:57:32 - 00:57:35)

**Laurie:** Me. Yep. Because that's the one that really pulls me in.



(00:57:35 - 00:57:36)

**Stacey:** Mhmm.



(00:57:36 - 00:57:36)

**Laurie:** And.



(00:57:36 - 00:57:37)

**Stacey:** K.



(00:57:36 - 00:57:40)

**Laurie:** Says, we understand. You know, we're here to help.



(00:57:40 - 00:57:41)

**Stacey:** Got it.



(00:57:41 - 00:57:49)

**Laurie:** No. We know you're going through a lot. So that one to me would instantly get my attention and get me to read all the rest of it.



(00:57:49 - 00:57:49)

**Stacey:** Okay.



(00:57:51 - 00:57:52)

**Laurie:** So,



(00:57:52 - 00:57:56)

**Stacey:** And where would you go from there? Like, what how would you process the order?



(00:57:58 - 00:58:01)

**Laurie:** I'd probably go to LD at that point.



(00:58:01 - 00:58:01)

**Stacey:** K.



(00:58:02 - 00:58:12)

**Laurie:** It talks about the collaboration within the SMA community, so that also gives me reassurance that there there's a dialogue.



(00:58:13 - 00:58:13)

**Stacey:** Okay.



(00:58:13 - 00:58:15)

**Laurie:** Between the company and people like me.



(00:58:16 - 00:58:17)

**Stacey:** And then wherein.



(00:58:17 - 00:58:17)

**Laurie:** Our.



(00:58:17 - 00:58:18)

**Stacey:** You don't.



(00:58:18 - 00:58:19)

**Laurie:** Are hard. You know?



(00:58:19 - 00:58:23)

**Stacey:** You don't need to justify your order per.



(00:58:22 - 00:58:23)

**Laurie:** Okay.



(00:58:23 - 00:58:24)

**Stacey:** Se at this stage,



(00:58:25 - 00:58:26)

**Laurie:** Okay.



(00:58:25 - 00:58:28)

**Stacey:** But would love to just kinda capture your order.



(00:58:29 - 00:58:35)

**Laurie:** Okay. So after that, probably the one below it, l y,



(00:58:35 - 00:58:36)

**Stacey:** K.



(00:58:39 - 00:58:40)

**Laurie:** And then HV,



(00:58:40 - 00:58:41)

**Stacey:** Mhmm.



(00:58:45 - 00:58:48)

**Laurie:** CP, CF, SL.



(00:58:49 - 00:58:53)

**Stacey:** Okay. Okay. Got it.



(00:58:52 - 00:58:54)

**Laurie:** That's that's the order I would do.



(00:58:54 - 00:59:03)

**Stacey:** If I forced you to identify the top two most important messages out of the seven that we have here.



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

**Laurie:** HQLD.



(00:59:04 - 00:59:10)

**Stacey:** Okay. Boy, that did not that did not require a thought.



(00:59:10 - 00:59:12)

**Laurie:** I'm a girl who knows her mind.



(00:59:12 - 00:59:17)

**Stacey:** I know why HQ, I feel like, because you've spoken about.



(00:59:17 - 00:59:18)

**Laurie:** Yep.



(00:59:17 - 00:59:22)

**Stacey:** That. And why LD? Why is that the other.



(00:59:22 - 00:59:22)

**Laurie:** Because.



(00:59:22 - 00:59:22)

**Stacey:** Really.



(00:59:22 - 00:59:23)

**Laurie:** It's.



(00:59:22 - 00:59:23)

**Stacey:** Important.



(00:59:23 - 00:59:23)

**Laurie:** It's.



(00:59:23 - 00:59:23)

**Stacey:** One here?



(00:59:25 - 00:59:41)

**Laurie:** Again, it it makes me feel like my voice is heard that they're they're listening to people within the SMA community. They're collaborate they're not just doing this on their own. They're actively collaborating with the SMA community.



(00:59:41 - 00:59:42)

**Stacey:** Okay.



(00:59:43 - 00:59:44)

**Laurie:** So I think that's reassuring.



(00:59:45 - 01:00:15)

**Stacey:** Okay. Got it. What just, like, what just really stood out for you today? We saw all of these different things. Was there anything that, like, okay. Wow. Like, that that that stuck with me or that had an impact on me, whether it's a message or a word or a phrase. Like, yeah, just where, if at all, was there impact in.



(01:00:15 - 01:00:15)

**Laurie:** You.



(01:00:15 - 01:00:15)

**Stacey:** All.



(01:00:15 - 01:00:15)

**Laurie:** Know.



(01:00:15 - 01:00:16)

**Stacey:** Of.



(01:00:15 - 01:00:16)

**Laurie:** What.



(01:00:16 - 01:00:16)

**Stacey:** It?



(01:00:16 - 01:00:17)

**Laurie:** I'm gonna say?



(01:00:18 - 01:00:18)

**Stacey:** Go.



(01:00:18 - 01:00:18)

**Laurie:** That.



(01:00:18 - 01:00:19)

**Stacey:** Ahead anyway.



(01:00:19 - 01:00:21)

**Laurie:** Can be a lot to manage.



(01:00:21 - 01:00:21)

**Stacey:** Yeah.



(01:00:21 - 01:00:21)

**Laurie:** That was the.



(01:00:21 - 01:00:22)

**Stacey:** Yeah.



(01:00:21 - 01:00:27)

**Laurie:** Really that was the one thing that I read today that I thought, yeah, it can.



(01:00:27 - 01:00:29)

**Stacey:** Yeah. Yeah.



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

**Laurie:** Yeah.



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

**Stacey:** Okay.



(01:00:29 - 01:00:31)

**Laurie:** Like that hits. You know?



(01:00:31 - 01:00:32)

**Stacey:** Got it.



(01:00:32 - 01:00:36)

**Laurie:** That was the one thing, and I'll remember that.



(01:00:37 - 01:00:45)

**Stacey:** Okay. Okay. Alright. Got it. I wanna go to h x for just a moment.



(01:00:46 - 01:00:46)

**Laurie:** Okay.



(01:00:49 - 01:00:56)

**Stacey:** I'm curious just if if there was anything new or helpful in Ajax.



(01:01:03 - 01:01:05)

**Laurie:** I don't I don't think so.



(01:01:05 - 01:01:05)

**Stacey:** Okay.



(01:01:06 - 01:01:09)

**Laurie:** I mean, I I know about the pals, so I know.



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

**Stacey:** Yep.



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

**Laurie:** That's what.



(01:01:10 - 01:01:10)

**Stacey:** Okay.



(01:01:11 - 01:01:11)

**Laurie:** What they did.



(01:01:12 - 01:01:30)

**Stacey:** Laurie, I'm curious, whether you had already had a sense for the fact that patients can appeal. In other words, an appeal doesn't have to just come from the doctor. The patient themselves can also appeal.



(01:01:30 - 01:01:30)

**Laurie:** Yes.



(01:01:30 - 01:01:32)

**Stacey:** To their okay. So that's.



(01:01:32 - 01:01:32)

**Laurie:** Yep.



(01:01:32 - 01:01:34)

**Stacey:** Something you were already aware of. Okay.



(01:01:34 - 01:01:35)

**Laurie:** Yep.



(01:01:35 - 01:01:35)

**Stacey:** Got.



(01:01:35 - 01:01:35)

**Laurie:** Yep.



(01:01:35 - 01:01:43)

**Stacey:** It. Got it. So I'm just giving my team just a second to see if there's anything.



(01:01:43 - 01:01:43)

**Laurie:** Mhmm.



(01:01:43 - 01:02:24)

**Stacey:** Else that they might want to and I'm doing a quick check here, see if there's anything else. I guess, while I'm waiting on them, the I I feel like you answered this very early in our conversation, but now that we've been through all of this, based on what you've seen today, is there anything that would, you know, you know, increase your likelihood to consider Everesty in the future? Or let me rephrase it. Did your lie did your likelihood to consider in the future stay the same, increase, or decrease based.



(01:02:24 - 01:02:24)

**Laurie:** Stay.



(01:02:24 - 01:02:24)

**Stacey:** On.



(01:02:24 - 01:02:24)

**Laurie:** This.



(01:02:24 - 01:02:26)

**Stacey:** Yeah. Okay. You had.



(01:02:26 - 01:02:26)

**Laurie:** Yeah.



(01:02:26 - 01:02:28)

**Stacey:** Indicated that earlier, but I wanted to be sure.



(01:02:28 - 01:02:28)

**Laurie:** Yeah.



(01:02:28 - 01:02:28)

**Stacey:** Yep. Got.



(01:02:28 - 01:02:29)

**Laurie:** Yep.



(01:02:28 - 01:02:29)

**Stacey:** It. Okay.



(01:02:30 - 01:02:31)

**Laurie:** Okay.



(01:02:30 - 01:02:38)

**Stacey:** Alright. I am not seeing any other questions come in, so I think we are good. Gloria, thank you. Truly a pleasure to talk.



(01:02:38 - 01:02:38)

**Laurie:** Oh,



(01:02:38 - 01:02:39)

**Stacey:** With you today.



(01:02:38 - 01:02:39)

**Laurie:** Really.



(01:02:39 - 01:02:39)

**Stacey:** I.



(01:02:39 - 01:02:39)

**Laurie:** Nice.



(01:02:39 - 01:02:39)

**Stacey:** Really.



(01:02:39 - 01:02:39)

**Laurie:** To.



(01:02:39 - 01:02:39)

**Stacey:** Appreciate.



(01:02:39 - 01:02:40)

**Laurie:** Speak as.



(01:02:39 - 01:02:40)

**Stacey:** It.



(01:02:40 - 01:02:40)

**Laurie:** Well.



(01:02:40 - 01:02:41)

**Stacey:** Thank you.



(01:02:42 - 01:02:42)

**Laurie:** Alright.



(01:02:42 - 01:02:42)

**Stacey:** Bless.



(01:02:42 - 01:02:42)

**Laurie:** Have.



(01:02:42 - 01:02:43)

**Stacey:** You.



(01:02:42 - 01:02:43)

**Laurie:** A good day.



(01:02:43 - 01:02:44)

**Stacey:** Take care. You too.



(01:02:44 - 01:02:44)

**Laurie:** You.



(01:02:44 - 01:02:44)

**Stacey:** Bye.



(01:02:44 - 01:02:45)

**Laurie:** Too.



(01:02:44 - 01:02:44)

**Stacey:** Bye.



(01:02:45 - 01:02:45)

**Laurie:** Bye.

