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Episode 13: Parenting **March 9, 2022**

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Mindy Henderson: Welcome to the Quest Podcast, proudly presented by the Muscular Dystrophy Association, as part of the Quest family of content. I'm your host, Mindy Henderson. Together, we are here to bring thoughtful conversation to the neuromuscular disease community and beyond, about issues affecting those with neuromuscular disease and other disabilities, and those who love them. We are here for you, to educate and inform, to demystify, to inspire and to entertain. We are here, shining a light on all that makes you, you. Whether you are one of us, love someone who is or are on another journey all together, thanks for joining. We've got a great conversation for you today. Now let's get started.

Mindy Henderson: Parenting is one of the toughest jobs on the planet. It's also, in my opinion, one of the best, most rewarding and credible things you can do. And today, we're inviting you in to listen to our coffee talk about our journeys through motherhood when a neuromuscular disease is also part of the equation. Each of our stories is different and we hope will bring you joy and encouragement. Please know this conversation is specific to our own personal journeys and is not intended to be used as medical advice or medical fact for anyone other than the individuals involved. Now let's take things off with some introductions. Sam, would you like to introduce yourself?

Samantha Przyby...: Sure. I will go first. My name is Samantha Przybylski. I'm a mom with SMA type 3, so spinal muscular atrophy. I use a power wheelchair full time. I'm no longer ambulatory. And yeah, that's a little bit about me.

Mindy Henderson: Okay, great. Erin, how about you?

Erin Pieper: Okay. My name is Erin Pieper. I'm 34. I'm a single mom to a nine year old and I have a disease called Friedreich's ataxia. You can call it FA for short. It's inherited and affects some of the body's nerves. It's caused by a gene defect and it's inherited from both parents. So both my parents are carriers, but they don't show signs of it. So they didn't even know about FA until I started having symptoms and then went through the line of doctors and diagnosis, and then it was learned that it was a genetic disease. So I'm living with that, and I use a wheelchair at this point, full-time. I did gradually go from a walker to using a wheelchair part-time, but now just use it full-time. So it's pretty much it.

Mindy Henderson: Great. Well, thank you both so much for that. Just because I am also a mother and a member of the neuromuscular disease community, I'll just go ahead and say also I do have spinal muscular atrophy as well, Type 2. So I was diagnosed. I was about 15 months old and we became parents through adoption. So I'm here also to share a little bit about my story as I guide us through the conversation. So it sounds like both of you have one child each. Did I get that right?

Erin Pieper: Mm-hmm (affirmative). Yes.

Samantha Przyby...: Yes, that's correct.

Mindy Henderson: Great. And remind me, Erin, you said yours is nine.

Samantha Przyby...: Right. I have a son Eli, he's nine.

Mindy Henderson: Okay. And Samantha, remind me how old yours is.

Samantha Przyby...: Yep. I have a daughter, named Scarlet, who is four.

Mindy Henderson: I love that name, Scarlet.

Erin Pieper: So do I. That's beautiful.

Mindy Henderson: Oh my gosh, and four is such a fun age.

Samantha Przyby...: It is.

Mindy Henderson: She keep you on your toes, I bet?

Samantha Przyby...: Oh, for sure. Yes, I'm very busy with her.

Mindy Henderson: Yes. That's amazing. Well, I'm going to just jump right in here and this is a meat subject and it's something that of course, has to be approached on a person by person basis. Parenting is so personal anyway, that becoming a parent and that whole journey, you've really got to consider your own circumstances and what the best way for you to become a parent is, if that's your journey. But Erin, did you grow up always wanting to be a mother? Is that something you always thought you would do?

Erin Pieper: I did, yes. Whenever I was asked the famous question, what do you want to be when you were up, I always had kids in mind. So from a very young age, that was definitely something I wanted. And it used to be like four or five kids.

Mindy Henderson: Oh my God.

Erin Pieper: But now that I have one and that I have the FA I'm like, "Nope, one's fine. That's it."

Mindy Henderson: So it sounds like we all each have one child a piece. And honest to goodness, my hat is off to anyone who has more than one because it's a lot of work.

Erin Pieper: Uh huh (affirmative).

Samantha Przyby...: Totally agree.

Mindy Henderson: Samantha, what about you? Did you always want to be a mom?

Samantha Przyby...: I did. I grew up as the oldest of five kids. I was always helping raise them, helping take care of them. Loved playing house, loved having dolls.

Mindy Henderson: Yep.

Samantha Przyby...: It was just always something I wanted to do, for sure.

Mindy Henderson: Okay. Yeah, you mentioned playing dolls. I also grew up just always assuming that I would be a mom. And my sister and I grew up swaddling the baby dolls and feeding them their bottles and all of that good stuff.

Mindy Henderson: So Samantha, do you want to go first and just sort of talk about your journey. What factors influenced your decision on how you decided to be a mom and how it all went down, so to speak?

Samantha Przyby...: Yeah, it was kind of interesting. I graduated college and I moved away from home. I lived in Texas for a while, both in Dallas and San Antonio, and then moved to Phoenix, all for my job. I worked as a cytotechnologist.

Mindy Henderson: Oh, interesting.

Samantha Przyby...: Yeah. So looking at cells for cancer, actually a lot of pap smears for female and clients. And I wasn't sure, for a period of time, whether I was going to be a mom or not. I kind of have let those ableist thoughts kind of take over, like, "Maybe you aren't strong enough to do this, maybe your physical limitations are too much, maybe this just isn't in the cards for you."

Samantha Przyby...: And so I've kind of been thinking about that for some time. But all of a sudden, we were closer to my husband's family, so we had some more support. We had bought a house there. We had just settled in. And at that point I was like, "I think maybe this is what I would like to do." I also was 28th when I got pregnant

with Scarlett. And so I guess that biological time clock kicked in for me, like if you want to do this, maybe you should do it now.

Mindy Henderson: Yeah.

Samantha Przyby...: Which it's horrible to say, but we all have it and it does show up. So yeah, that, I guess, is kind of what went into it initially. And I guess being a first time parent, you get the joy of not knowing everything going into it.

Mindy Henderson: Right.

Samantha Przyby...: So you're kind of naive to go into things.

Mindy Henderson: It's true.

Samantha Przyby...: Yeah. SMA is a genetic disorder where, similar to FA, both parents have to be carriers in order for your child to have a chance of having it. So my husband and I talked about it and we decided we were going to do carrier testing on him and see where that led us before we made any big decisions. So we did the carrier testing, which is not paid for by insurance, that's out of your own pocket, and he turned out not to be a carrier. So we didn't have to explore other avenues initially. So the other option would've been to do IVF, had he been a carrier and then selecting embryos for that. I know that's not everyone's desire to even do carrier testing or take that on, which is fine, that's a choice. This is just another choice we made. Yeah.

Mindy Henderson: Yeah.

Samantha Przyby...: I don't want to write that off, like this is how you have to do it. Of course, it's not, this is just how I did it.

Mindy Henderson: Yeah. It's just it's information that's available if you want it. And I think that it's amazing that we live in a day and an age where you can get that information available to you. Were you pretty much looking at trying to have a child biologically right from the get go or did you consider other options?

Samantha Przyby...: Yeah. Initially, I wanted to do it myself. I was open to other options if this wasn't going to work out for whatever reason. But my doctor gave me the go ahead. He said, "You're healthy otherwise, other than having SMA. And so if you want to start trying, you can." I'm willing to take this on. And so we did and we were pregnant a month later. So I guess it was meant to be.

Mindy Henderson: That's wonderful. Well, I want to come back to you and I want to talk some more about some of the medical considerations and things that you talked about with your doctor. But first, let me go to Erin. Erin, do you want to talk us through what your journey looked, I guess, to decide? Because you also had a biological child. And so let's talk about what got you there.

Erin Pieper: Yeah, sure. So I like to say that my pregnancy was kind of a spontaneous thing. It was not planned. I'm not married, so I was more so in a brief relationship at that point. So when I found I was pregnant, I had all through what ifs going through my head.

Mindy Henderson: Yeah.

Erin Pieper: I was still, at that point, coming to terms of FA myself, because I'd only been diagnosed about a year at that point.

Mindy Henderson: Oh, okay.

Erin Pieper: So I was still walking independently. But if you were around me for a long period of time, you would probably notice that like my gait looked a little different. But again, I was still processing it. I was kind of in denial for a little bit about talking about it. So my child's father actually didn't even know I had FA.

Mindy Henderson: Okay.

Erin Pieper: So once I had a feeling, "Hey, surprise," then I had to drop the other bomb that I had FA. So he knew nothing about it. He's still probably coming down from a little bit of shock about pregnancy and then I'm trying to explain FA and it was a lot. And like Sam had said, getting tested, it was all out of pocket. So we definitely went that option. He probably wanted to do more than I did because to me, I was like, well I'm pregnant, I'm going to have this child no matter what. But we did go through the process of getting him tested. But for some reason, I don't know how this happened, but they ran his test wrong. So we never got a clear answer.

Mindy Henderson: My goodness.

Erin Pieper: Yeah. So for Eli to have FA, he would have to get it, with the carrier from both parents. So since I have FA, Eli definitely will get the carrier gene from me since I already have it. So it's up to Eli's dad, whether he's a carrier or not. So if he were a carrier, Eli would have a 50% chance. If he's not, he's good.

Mindy Henderson: Okay.

Erin Pieper: But we never went and redid it. I talked to my neurologist a lot about it and he was like, "You know what? You're probably going to stress yourself out. Because let's say for example, Eli's dad tests positive, you still will not know for certain if Eli has it."

Mindy Henderson: Right.

Erin Pieper: And they're like, "You're just going to worry yourself." He's like, "Why don't you wait until Eli is, when he is walking a little better and whatnot. If you notice anything off, then just get him tested." So I'm really glad I took that advice because it's not come to my mind once.

Mindy Henderson: Yeah.

Erin Pieper: And Eli's nine. So I would like to think that maybe I would notice something by now, but I really don't. It's all up to God.

Mindy Henderson: Yeah. Well, I'm glad that it's proven to be sort of a low stress consideration for you. And obviously, we will think good thoughts and send all of the positive juju your way.

Erin Pieper: Thank you.

Mindy Henderson: That he'll continue to be healthy. Well, actually, before I ask my next question, I guess I'll share what my journey looked like. I suspect that I'm a little bit older than the two of you probably. And so I think that when I was looking at becoming a mom, it was like 17 years ago, I'm going to date myself a little bit. You guys all know that they're finding things out about our condition all the time. And so when I was looking at expanding my family, my husband and I had been married for about two, three years and we were beginning to talk about it. I had told him, because doctors pretty much my whole life had said that they really didn't think that it was in the cards for me with my particular condition. They didn't know as much about what circumstances it would be passed on and the risk to me.

Mindy Henderson: And so all of the advice that I got along the way was that it was better to err on the side of caution and look at other ways to become a mom. So I'd had that conversation with my husband and we had always thought that when the time came, we would adopt. And so, after we'd been married a couple of years, we started going down that path. And ultimately, we adopted a daughter from China who was five when we adopted her. We decided to look for an older child because there was such a need to place older children. And also, I was concerned too about my ability to do things like change diapers and pick her up when she was crying and things like that, that I desperately want to ask you guys about how you navigated those things. Because that was one of my thought processes that deterred me from going the biological route.

Mindy Henderson: And I will say that I have the most incredible daughter on the planet. She's 20 now, about to be 21. But that was our journey. So a little bit different than what the two of you, the way that you all became moms. So Sam, I'd love to go back to you, and like I said, my doctors were not keen on the idea of me with SMA. I kind of wonder if the type of SMA that you and I each had. I have SMA 2, and I think you said you have SMA 3.

Samantha Przyby...: Right.

Mindy Henderson: And I wonder if that may have had a bearing on, all this to say, I think ask your doctor if you're listening to this.

Samantha Przyby...: Yes.

Mindy Henderson: Good advice. But what are your thoughts and what kind of conversations did you have with your doctor about what the health implications could be to you?

Samantha Przyby...: Definitely. Looking back on my journey with my OB/GYN, I think I could have done a better job and maybe he could have said, "I don't really have the expertise to really take this on necessarily." He did a phenomenal job. Everything worked out. However, looking back on it, I don't think either one of us were very informed. It was kind of like we were just both leading each other through the dark kind of situation.

Samantha Przyby...: Since my SMA had been stable for most of my adult life at that point, I had really aged out of any of my healthcare resources. So I hadn't been to any specialist within probably the past 10 years when I got pregnant. I had gone to my pediatric specialist prior to graduating college and leaving the state. But after that, I had never reestablished care in any of those places. So essentially what I did is I went and found a good OB/GYN and not necessarily one who did high risk cases or specialized in this or anything like that. And I just kind of said, "This is what I'm going to do. Would you like to be a part of it?" And he was like, "Sure." So I feel like if you're able to find those resources, you should, just for later on in the pregnancy.

Mindy Henderson: Definitely.

Samantha Przyby...: I didn't have any complications or anything like that, that popped up, but I easily could have, I believe.

Mindy Henderson: Sure.

Samantha Przyby...: Given the circumstances.

Mindy Henderson: Absolutely. Were you on bedrest at all?

Samantha Przyby...: I was not. I actually worked full-time up until like the day before my scheduled C-section.

Mindy Henderson: You're a warrior.

Samantha Przyby...: I know. I know. And I don't know if that's good advice either. It was really hard on my body at the end and I needed a lot of help. Luckily, I had great coworkers helping me at work with whatever I needed. My husband worked nearby, so he was able to come to my job to help me use the restroom or transfer me because at the end, I couldn't transfer myself at all just due to the weight gain, which you have with pregnancy.

Mindy Henderson: Yep.

Samantha Przyby...: Yeah. So it was interesting. And it was more out of being naive that this all occurred. So I don't know if I would go about it the way I did, but that's how I did do it.

Mindy Henderson: Well, clearly it worked out for you.

Samantha Przyby...: It did. It worked out, yep.

Mindy Henderson: Yeah. I'm glad that everything turned out so well and you didn't have complications. I'm curious though, did your doctor put any complications on the table that you needed to watch out for?

Samantha Przyby...: Not necessarily. He was like, "You're healthy, otherwise." My blood pressure was good. I didn't have gestational diabetes. The baby was growing properly. The only thing we were kind of iffy on was how I was going to deliver. So was I going to be put fully under or were they going to be able to place an epidural for anesthesia purposes?

Mindy Henderson: Okay.

Samantha Przyby...: And ultimately, we decided on putting me completely under for the delivery, just because I had had a spinal fusion and I had rods, and all the hardware would've made placing an epidural very difficult.

Mindy Henderson: Okay.

Samantha Przyby...: Also, my own medical fears, I guess, I much preferred to go under which isn't always the case for people. My anxiety around medical situations is really, really high. So I was happy to go to sleep for that. [crosstalk 00:21:53]

Mindy Henderson: And to wake up to a beautiful baby.

Samantha Przyby...: Yeah. Exactly. It didn't seem that bad to me. I know that not everyone wants that experience, but it was the safest, best option for my particular situation.

Mindy Henderson: Right. Okay. And so Erin, I know that you said that you had just been diagnosed a year before you found out that you were pregnant. What kind of conversations did you have with your doctors about what pregnancy was going to be like for you and any health implications that you needed to be aware of?

Erin Pieper: Yeah, for sure. So everything for me was kind of fast tracked since nothing was planned. And I was pretty much learning everything as they [inaudible 00:22:40], for me. But I knew actually, my very first question to my neurologist when I was diagnosed, so that were to been about a year or two prior to pregnancy. My first question was, "Could I have kids?" Because that was something I always wanted in my life.

Mindy Henderson: Yeah.

Erin Pieper: And he had said, "Yeah, a lot of people with FA have children, get married, have a job," like the average Joe kind of stuff. So he was like, "Definitely, it's in the cards for you. Don't feel too scared about that when the time comes." So I knew going into it when I found out that it probably wasn't going to be too difficult for

me because I really didn't have any other health issues even related to FA at that point. Because later on, I can get cardiomyopathy, some people get diabetes. There's a list of things. So actually, at that point, I didn't have anything. So I knew it was pretty healthy going into it. And sure enough, when I went to the doctor and spoke to my neurologist, went to the OB and did all that checklist stuff, everything seemed to be okay. So I really wasn't too concerned. My only thing was, as my belly was growing, my balance was getting worse.

Mindy Henderson: Oh, sure.

Erin Pieper: So I did have a really bad fall when I was about two or three months pregnant and I felt directly in my belly.

Mindy Henderson: Oh no.

Erin Pieper: So I freaked out, went to the ER and everything checked out. But it was in that moment where I was like, okay, I need to stop being stubborn and look at an assisted device. Because at that point, I was still like, if things were getting hard, I'd grab someone's arm or brush up against the wall or grab railings. So it was just getting hard with a growing belly. So I started using a walker when I was about three or four months pregnant. A lot of that was just a huge learning curve for me, for everything I mean. It was the FA, the pregnancy, getting ready to have a baby. Everything was thrown at me. So I pretty much just learned, as I was rolling with the punches kind of thing.

Mindy Henderson: Yeah.

Erin Pieper: So I used the walker for a bit and I used that for about a couple years after Eli was born. So I was still kind of standing upright. So if I was leaning on a dresser, I could change his diaper standing up. Obviously, I felt more safe when I would sit on my bed and do it that way. I could lean against the sink and prepare food and clean and do enough. But obviously, as FA progressed, because it is a progressive disease, I started taking more advantage of the wheelchair. And then I had another really bad fall maybe five years ago and I broke a rib. And that was super painful.

Mindy Henderson: Yeah.

Erin Pieper: And so I used the wheelchair to get around while that was healing. So once that was kind of healed up, I just got so used to using the wheelchair and I just felt safer using it, and got from A to B quicker. Using the walker was always super intense and looking around like, and I would fatigue easier. So here I am now, I'm just using the wheelchair full time.

Mindy Henderson: Yeah. And would both of you say that your health went back to the original state that it was after you had your babies or do you feel like there were longstanding effects that maybe you didn't completely gain back the strength or the function that you had before?

Erin Pieper: So where I was when I delivered Eli, that was where I was, and then I progressed from that point.

Mindy Henderson: Okay.

Erin Pieper: So I never went back.

Mindy Henderson: Okay.

Erin Pieper: I think that speaks a lot of truth with FA because your nerves, certain nerve endings that can control coordination and whatnot, it's like once the damage is done, you don't reverse and go back.

Mindy Henderson: Yeah. Okay.

Erin Pieper: So that was me. It was, at that point, just getting worse. Okay, I see. Samantha, what about you?

Samantha Przyby...: Yeah. For me it was the waking at the end had caused me to stop transferring on my own, to the toilet or to the shower became difficult by myself. And that probably went on for a few months. In that time and then after delivery, healing, by the time I was able to get back to trying those things, I had lost too much of my muscle mass control, whatever you want to say, in order to go back to transferring on my own. And I never regained it after that.

Mindy Henderson: And I ask that question just because I think there's so much about motherhood that is made up of sacrifices. I think everything that we do is in the interest of our children. Our children come first. And in so many areas of our lives, we make sacrifices. And honestly, I think that bringing your children into this world and having some long term effects to your health is kind of the ultimate sacrifice. Right? And maybe not the ultimate, but it's a big sacrifice that I think that your children, one day, will probably recognize and see what an amazing thing it was that you did.

Samantha Przyby...: For sure. I think, yeah, hindsight, getting to view your parents as a parent is a pretty amazing thing.

Mindy Henderson: It's true. Okay. So I have to ask some of these questions because not having gone through a pregnancy myself, I am so curious how you guys handle certain things. So the first one that I want to ask about is I've heard so many people, so many of my own friends who don't have the same health conditions that I have, talk about the end stages of pregnancy and how hard it is to breathe and to be comfortable at night. Because I know that with our conditions, our respiratory systems can be a bit compromised anyway. So how did that all manifest for the two of you?

Erin Pieper: Yeah. So the end stages were super uncomfortable. Super. I ended up, right after I had Eli, I bruised my coccyx, that bone in your tailbone. I fell down a lot my final month. Sitting, putting that pressure right on your tailbone, that was

really, really hard. I was not sleeping. Get out of here. I felt I slept like on and off, every 30 minutes. I could never find a comfortable position. And I have one those, I don't even know what they're called now, I feel like pregnancy was so long ago, but it was like one of those U-shaped pillows.

Mindy Henderson: Oh, sure. Yeah.

Erin Pieper: It kind of keeps you like on your side.

Mindy Henderson: Yes.

Erin Pieper: Because they always say, you're not supposed to lay on your back when you're pregnant, and I'm a back sleeper. So that was super hard for me. And I woke myself up a lot and I was laying in my back. And I was always trying to shift my body over and the weight of the belly was so hard. And my other biggest pregnancy side effect was the heartburn. I could not pop enough Tums. It was like candy to me. Right at the end there, it was constant.

Mindy Henderson: Wow.

Erin Pieper: It was really bad too. I always felt like my esophagus was on fire.

Mindy Henderson: Oh, bless your heart. Oh, my God.

Erin Pieper: I know, it sucked. But those, I guess, were my biggest. I will say I was pretty blessed, I feel, that I didn't really have the [inaudible 00:32:10] of pregnancy. Yeah, considering my FA and my physical limitations, but pregnancy overall wasn't horrible. I wasn't on bed rest or vomiting the entire time like some people.

Mindy Henderson: I was going to ask about that too, because if you've got any mobility issues, any kind of sickness that takes you to the bathroom is kind of a challenge. It didn't sound like you had much in the way of morning sickness, Erin?

Erin Pieper: Only in the first trimester, and I was like clockwork with what they had said. They were like, "Your first trimester, you're probably going to be very nauseous. But when your second trimester hits, you're good." And that's exactly how it was for me. I don't think I ever really actually got sick. But for the first three months, I was nauseous about everything. And I would get a really bad whiff of something and I'd be like, "Oh my God."

Mindy Henderson: Oh no.

Erin Pieper: My senses were super heightened and everything just wanted to make me gag.

Mindy Henderson: Wow.

Erin Pieper: But once that second trimester hit, I felt like a million bucks. I was like, "Man, they were right. You really do feel that." So good.

Mindy Henderson: Did you have any super weird cravings?

Erin Pieper: Breakfast food and French fries.

Mindy Henderson: Okay.

Erin Pieper: It's funny because I still crave French fries to this day. That's my favorite food. But all I ever wanted was all the breakfast foods, like all of it.

Mindy Henderson: Interesting.

Erin Pieper: Eggs, bacon, biscuits, waffles, I wanted everything.

Mindy Henderson: Okay. I crave those things as well and I don't have pregnancy to blame. Samantha, what about you? What about the breathing issues for you, when the baby is big enough to kind of push up into your ribs and your chest area, was that a problem for you?

Samantha Przyby...: Yeah. It got very uncomfortable at the end. With the spinal fusion, not being able to bend your spine or have that help in any way, it made her really, really pushing on my ribs. And your breathing is difficult, like shorter breaths, I guess you would say. It's hard to get a good deep breath at the end. But it's temporary. The end of pregnancy is just really, really hard. You're very, very uncomfortable.

Erin Pieper: Yeah.

Mindy Henderson: And I think anybody would say the same thing.

Samantha Przyby...: Yeah.

Mindy Henderson: Did you find anything that worked for you to help keep you comfortable so that you could sleep, or any of that?

Samantha Przyby...: I did not love my pregnancy pillow. I hoped I would, but I did not.

Mindy Henderson: I hear you love them or you hate them.

Samantha Przyby...: Yes. I hated mine so much. So it was just like trying to position in bed better. But yeah, my husband would have to roll me. I couldn't roll myself back and forth. I guess, at that point though, you're so exhausted that sleep is welcomed most of the time at the end.

Mindy Henderson: Yeah. That makes sense. Okay. The million dollar question. I hear that from day one, and I'm speaking from complete ignorance here and only things I've heard, but I hear that from day one, you have to use the restroom, like every five minutes, which for me would be a huge problem.

Samantha Przyby...: Yeah. It was a huge problem.

Mindy Henderson: Yeah. How did you handle that?

Samantha Przyby...: So I'm a terrible patient. I actually ended up being like really swollen because I wasn't taking enough water.

Mindy Henderson: Yeah.

Samantha Przyby...: Just because as a person with SMA, I don't drink that much water.

Mindy Henderson: Right. Same.

Samantha Przyby...: Because it's hard to go to the bathroom.

Mindy Henderson: Yeah.

Samantha Przyby...: And that's like a real life thing. Also, I was at work. I can't be going to the bathroom constantly, or an able bodied person who can just run to the bathroom and take a few minutes, no big deal. But for me, it's a 15, 20 minute process. Right?

Mindy Henderson: Right.

Samantha Przyby...: To transfer, to transfer back, to get dressed, undressed, it's just a lot. So a lot of my pregnancy, I was really swollen because I didn't drink enough. And I found it actually more terrible at the end of my pregnancy. At the beginning, I was still able to transfer relatively well. But at the end, with all the weight pushing down, because you're sitting and not being able to transfer myself, the end was the worst for me, as opposed to the beginning. Yeah.

Mindy Henderson: Yeah. And you said that your husband worked close by, so he was able to come and help out?

Samantha Przyby...: Yeah. My job was fantastic about it all. Sometimes my coworkers would help me and no one would say anything. And then we had a gender neutral bathroom, like in the gym, where it was just a one bathroom stall kind of deal. And so my husband would come. He worked like a block away and he could transfer me in there and help me.

Erin Pieper: That's nice.

Mindy Henderson: Sounds like both of you had really understanding, accommodating employers.

Samantha Przyby...: Yes, immensely.

Mindy Henderson: That's so great.

Samantha Przyby...: Yeah. I don't know what I would've done had I not.

Mindy Henderson: I love hearing that. I love hearing that. What about you, Erin? Was this an issue for you at all?

Erin Pieper: It feels like so long ago, I kind of forgot. But I don't feel like it was that bad in the beginning. If it was, my belly wasn't too big that it wasn't terribly hard to go to the bathroom constantly. I would say that the physical limitations more so when I was four or five months pregnant, when I used the walker. But still kind a little easy to get in the bathroom and just pull my pants down and go and then walk out of the bathroom. So the process wasn't too bad. But definitely towards the end, I would say I could probably just live on the toilet.

Mindy Henderson: Right.

Erin Pieper: Because the baby kicks your bladder and you're like, "Oh my God." You feel like you're going to go right then and there.

Mindy Henderson: Yeah. Yeah, seriously. I'm so sorry to any gentleman who are listening right now. But this is what we go through.

Erin Pieper: Yeah. Real life.

Mindy Henderson: It's true. It's true. And Erin, I don't think I asked you, were you on bed rest at all during your pregnancy?

Erin Pieper: No, I wasn't. No.

Mindy Henderson: Okay.

Erin Pieper: And Eli was actually born on his due date. So what Sam had said, I had a lot of those concerns with my doctors about should we knock her out, do general anesthesia, do a C-section, do a natural birth. That was my plan because that was what I wanted, a natural. But Eli didn't turn around. He was breech up until I went in.

Mindy Henderson: Oh, little stinker.

Erin Pieper: I was induced two times. And I was only dilated two centimeters at the end of my second induction. And my doctor was like, "Why don't you just go home and let nature run its course." And I was like, "No way, I've been here 48 hours. I made it this far, I'm not giving up." And she was like, "Well, we can break your water. But if we break your water and nothing is starting to happen with so many hours, we will either have to do with C-section or knock you out and take him that way." And at that point I was like, whatever. I was so frustrated because I had been there two days and I was like, something needs to happen. So right when she broke my water though, my contractions were full force and Eli flipped. It was only a few more hours.

Erin Pieper: And I did get the epidural and that was something they were a little leery about at first because anyone's at risk for nerve damage. But I already have a disease that I have tons of nerve damage.

Mindy Henderson: Right.

Erin Pieper: So that was like, do I want to take that risk? So I tried for two or three hours without, but the pain was just so intense and I ended up giving in and getting it. And luckily, everything was fine. But I was only numb on one side. So I still could move my right leg and my right toe. But I wasn't feeling the contraction. So I was like, "No big deal. I don't care. At least I don't feel it." Yeah, that was my story. And then I only had to push like 20 minutes, which again is pretty unheard of because a lot of people do that for hours, even into a day.

Mindy Henderson: Oh yeah.

Erin Pieper: And I was so fortunate and I didn't push very long and he was here. So it all worked out in the end. But my OB probably wasn't that hip on FA. And obviously, with me still coming to terms with it, I didn't really know how to fill her in because I didn't know what was going on.

Mindy Henderson: Right.

Erin Pieper: So again, if I were to go through this process again, it would be so different.

Mindy Henderson: Right.

Erin Pieper: I'd make sure my OB being was 100%, knew what FA was, maybe have high risk doctors on call. Everyone was just kind of scrambling because FA, no one really knew about it. The nurses didn't know about it and they're like Googling while I'm sitting there. Oh God.

Mindy Henderson: Oh my gosh.

Erin Pieper: This is not going to be good.

Mindy Henderson: Yikes. Well you two are my heroes, seriously. I got 1,000 more questions I would love to ask you guys. But so let me ask you about the actual experience of motherhood because when they're babies and infants, so much of their care is so physical. Like I mentioned a little while ago, picking them up when they cry and changing their diapers and grabbing their hand before they stick it in an electrical outlet and all of those sorts of things. Sam let's start with you. How did you problem solve for those things and what are your best tips for how you made those things work?

Samantha Przyby...: Yeah. The beginning is really hard. I knew going into it I wouldn't be able to lift her or change her or do those aspects of her care, like I physically wouldn't be able to. So it was knowing that I would have to have my husband there or family or a friend pretty much at all times in order to have them be able to hand me her or set her on my lap or change her. So the first year is really hard because... I love the newborn phase, but it got so much better after. She was about a year old for me to be able to be more of a parent in that regard to her. So it was more like getting over myself in order to help her, in the beginning kind of a thing.

Mindy Henderson: I love that you said that because I said before, it was a consideration of mine and one of the reasons why we adopted. But you're right, I kind of read that about myself and how I would feel.

Samantha Przyby...: Yeah.

Mindy Henderson: Yeah. And it's not about me.

Samantha Przyby...: No, it's not about me. So it was whatever I could do or who could ever help her in order to help meet her needs. So not everyone was going to do it exactly how I would, not everyone was going to do it to my standards, but I had to be okay enough with it in order to get her the care she needed.

Mindy Henderson: Yeah.

Samantha Przyby...: But I tried to be a part of everything that I could. Like washing bottles, I could do that. I had made a whole washing station on my table since I couldn't reach the sink. And picking out the outfits and making sure we had all the supplies ordered. And so just taking a different view of it. I tried to take some of the burden off in the ways that I could from everyone else around me.

Mindy Henderson: That's so good because you're right, so many things in life that are hard, period, it's all about your perspective. And I love that you were able to shift your mindset and look at the things that were still in your span of control that you could own and be in charge of those things. I love that.

Samantha Przyby...: Yeah. It was very hard, very rewarding. And after the newborn stage, when Scarlett was finally able to stand and walk and crawl and be able to help me out with those things, so I could communicate to her, "Could you crawl on the couch and I can change you there? Could you help me get you from point A to point B by stepping up on my wheelchair?" And just learning one another in that way, it got so much better in that regard for me.

Mindy Henderson: That's so great.

Samantha Przyby...: So it's just that first year that's really, really tough and you need a lot of support to make it happen.

Mindy Henderson: That makes sense. Erin, what about you? What about that first year and how did you handle it?

Erin Pieper: Yeah. So my biggest thing that I really beat myself up about was not being able to stand up when he was crying. So like most babies, they love when you're standing and holding them. So I would always have to sit and hold him. It would work, for the most part. But if there was other people around that could stand up, they would take him. But like what Sam had said, I would definitely take advantage of the things that I knew I could do. So even though they were small, they meant a lot to me. So being able to even mix his bottles and clean them or do the laundry and fold his clothes, which a lot of people would just hate doing

all that. But knowing I could do it was my participation. It was something I could do, so I took pride in that.

Erin Pieper: And I could hold him, play with him, do everything, but it just was from a sitting down position. So before Eli walked, the house I was living at, at the time, luckily didn't have any stairs. It was just like a slab home. So when I would have to maneuver him from point A to B throughout the house, I would put Eli in a stroller and I would just push him around that way. So that was our thing up until... Well, he was an early walker, so he was about nine months. So that was what we did for nine months. If I had to go from bedroom to bedroom, or kitchen to bedroom, just stroller. And then one of those Pack 'N Plays. So he slept next to my bed. So whenever he'd wake up, like every four hours to want to eat, change his diaper, he was right there. So I could lift him up, put him in the bed with me and be dealing with that.

Erin Pieper: But yeah, the more independent they get, it's easier. Nine could just be a very trying age, but I notice a lot more, and I think it's also just what they're into at that age.

Mindy Henderson: Yeah.

Erin Pieper: Like right now, we have a lot of, I find, I have a lot of struggle even though the physical part isn't as hard. Because obviously, he can fend for himself and do a lot more. But they're always going through a phase and you're always trying to catch up to what they're going through at that moment.

Mindy Henderson: Yes.

Erin Pieper: There's always something and there's always going to be a little challenge. And I think I'm just at that point where I'm like, I just need to accept every year, there's probably going to be something that's challenging for me.

Mindy Henderson: Yeah. Oh, I think every two weeks there could be something new that's challenging.

Erin Pieper: Yeah.

Mindy Henderson: I don't know, I might be stereotyping, but I feel like little boys are so hard to keep up with.

Erin Pieper: Yes. And he is all over the place.

Mindy Henderson: Yeah.

Erin Pieper: Yeah. That energy, I'm like, "Oh my gosh." If I could just bottle that up and give it to me, I would be so productive and get so many things done. He is just all over. But he is so sweet and I would say he's never known me not to have FA, or I use the walker and a wheelchair, so he's always seen that.

Mindy Henderson: Yeah.

Erin Pieper: He needs to lend a helping hand or do something. And he knows what I can and can't do, and he'll just hop right up and do it. There are times I could say he gets frustrated and that could also be the age thing. It's just like, "Again? Do I have to do that?" Or, "Can you do that? Come on."

Mindy Henderson: Right. Right.

Erin Pieper: And I try to understand those boundaries and be like, okay, I'm asking too much. I didn't want to put too much burden on him either. But this is our deck of cards, so we're going to play them.

Mindy Henderson: Exactly. I remember one time when my daughter was still pretty young, she was probably five or six. And I took her to movie and this darn bag of Skittles that I bought for her to eat during the movie between the two of us, we eventually got it open. But it's little things like that.

Erin Pieper: Yeah. I've run into those problems all the time, so I know what you mean.

Mindy Henderson: Oh my goodness. Yeah. So let me ask you, what do you feel like have been the best parts of being a mother, for you guys? Sam, let's start with you.

Samantha Przyby...: I think the best part of being a mom was getting to know who my child is, watching her grow and learn and just getting a front row seat to getting to see who she will become eventually. And just being that support system for her and seeing where that goes. It's so exciting.

Mindy Henderson: It's true. It's true. Before we adopted my daughter, I used to think all the time, who is she going to be?

Samantha Przyby...: Yeah.

Mindy Henderson: Is she going to be an athlete or a dancer or an actress or a mathematician, or is she going to be funny or quiet?

Samantha Przyby...: Exactly.

Mindy Henderson: [crosstalk 00:52:19] Watch it all unfold. What about you Erin? What's your favorite part of being a mom?

Erin Pieper: I have to go with what Sam said. That is, it's so rewarding to watch them grow. And just the unconditional love. It is so unconditional. Nothing will change it. I always call him my favorite deputy. So he will always be my favorite deputy. And it's wonderful to watch them grow in the phases they're at, it's just fun to be a part of.

Mindy Henderson: It is. It's so good. And actually, Erin, I'm going to go back to something you said a second ago, because it's been such a big deal in my parenting journey. I feel like

raising children when you have a disability, I feel like you can't help but raise these sensitive, compassionate people that they turn into, it's like you said a minute ago, I can remember my daughter being seven or eight and we would be out running an errand or doing something and she would just reach for something and hand it to me because she knew that I wasn't going to be able to reach out and get it. And she just knew. They sort of instinctively take on, not exactly a caretaker role, but they just become these compassionate people who know instinctually some of things that you need and they just do it without question.

Erin Pieper: I love that. When I see Eli do that, I'm like, "Ooh." He really is so super empathetic towards me. But to other people, he is. He's a very sweet kid. And I think that's really going to help him when he grows older. And I can see that he's going to be quite the gentleman knowing...He knows so much about helping someone.

Mindy Henderson: Yeah. It's true. It's true. So I can't ask that question without asking the opposite question. Sam, what's been the most challenging part of being a mom?

Samantha Przyby...: I feel like for me, it wasn't... Obviously, you know you're going to have challenges as a mother and with your child and all of that. But I think it was figuring out this new version of me after I had her. And I guess just kind of learning how to let that past version go and welcome this new version, because I think you change so much. As much as people say, "Oh, I would never change after I had a kid."

Mindy Henderson: Yeah, no, you do.

Samantha Przyby...: You do, for the better.

Mindy Henderson: Yeah. Your whole identity changes, doesn't it?

Samantha Przyby...: Yeah. Yeah. And it's for the good and it's for the better, and it's just kind of figuring that out.

Mindy Henderson: That's really good. That gave me goosebumps a little bit. Erin, what about you? What's been the hardest part of being a mom?

Erin Pieper: The physical limitations are very hard. I feel I've done the best I can to accept that and come to terms on what I can and can't do, and to not dwell about the things I can't. And to just try and find the love and the things that I can do.

Mindy Henderson: Yeah.

Erin Pieper: But there are times that it stings. When Eli was like, "Come outside," and he wants me to play soccer with him, which I would say I can't. And he'll be like, "Can you just watch me?" Which I enjoy, but sometimes it stings. You're like, "It'd be so nice to just get out there and run around with him." Or something does happen, like just for an example, he's upstairs and I'm downstairs. If I had

to get up there, I can't just run up the stairs and be up there. It's like a whole process to transfer into a chair lift and then transfer into another wheelchair. So it's just those little things that people really do take for granted, just you can hop up and run or skip and do something that it really takes me a lot of time to do stuff.

Mindy Henderson: Right.

Erin Pieper: There's times that I'm just very exhausted and he will be like, "Will you come upstairs and go outside with me?" And I'm like so tired that just the thought of even transferring from one chair to the next, I'm like, "Oh." But you do it for your kid.

Mindy Henderson: Of course.

Erin Pieper: Because again, it's not about you and it's not his fault that I have FA and I'm slower doing stuff. So I got to be there for as much as I can be.

Mindy Henderson: Right. Right. And then I'm sure, in his own way, he already even understands and just knows that this is mom and this is how she gets upstairs. I think for me, apart from some of the things that you both said, I think for me, one of the hard is things about being a mom, and I think this is a total product of how much we love them. But it's like, if my daughter has a bad day, I have a bad day because I want so badly for her to be happy and joyful and for everything to go her way. And if someone was mean to her at school or she had a problem, or we had words before she left for school or whatever. If she had a bad day, I had a bad day. I think that was one of the hardest things for me, because-

Erin Pieper: I feel that.

Mindy Henderson: Yeah. You just want so much for them. So in closing, what would you say to someone who's listening and maybe feeling ready to expand their family and they're currently weighing their options around how to make that happen? Sam, what's your best piece of advice for somebody?

Samantha Przyby...: Yeah. I guess, do your research as best you can. Make sure you have the support system to go into this. And I'm always happy to be a support system for someone. I'm happy to answer any questions that people might have that are specific. But yeah, the internet has made networking so much easier now, and there are people who do it and you can do it if you want to. And yeah, that's my advice.

Mindy Henderson: Absolutely. And I am going to put some information about how to get in touch with each of you, in the show notes. So if anybody wants to reach out, you can definitely look there. Erin, what's your best piece of advice for anyone looking to expand their family?

Erin Pieper: Pretty much what Sam had said. It really is just doing as much research and when you feel you've researched all your options and then you do it, go for it.

But you're never going to be 100% ready, and I think that's what is so beautiful about having children, is you learn a lot as they grow. And nothing that, well, I can't say nothing, but some things that you think will go to plan may not.

Mindy Henderson:

Right.

Erin Pieper:

And they might shift. So I just think you always need to have an open mind that when things don't go as planned, that you'll be okay.

Mindy Henderson:

That's so good. That's really, really good because you're right. I think even if you have 16 children right now, I don't think you're ever ready for the next one.

Erin Pieper:

Yeah. Right.

Mindy Henderson:

You never quite know it all.

Erin Pieper:

But you can be a little ready, especially when you have a disability. If you want to go through a checklist and do you genetics, or you want to make sure you're financially set, at a certain point, those are things that you can do to get your ducks in a row. You also need to leave room for the uncertain.

Mindy Henderson:

Absolutely. Absolutely. This has been so good. I absolutely loved speaking with both of you. I want to give y'all last word. Erin, any last thoughts that you would like to leave our listeners with or what is next for you?

Erin Pieper:

Well, I actually have a question for you guys, if you don't mind. So what are the different types? You of type two and Sam has type three. What's the difference?

Mindy Henderson:

It typically, and Sam feel free to jump in, but it typically has to do with the age of onset. So I think type 1 tends, and I'm not a doctor, but type 1 I think tends to be the most severe and has the earliest onset, usually I think maybe even at birth it's fairly prevalent or noticeable or detectable, I guess maybe I should say. Type 2 Usually it's diagnosed in infancy. Like I said, I was diagnosed at about 15 months. And then SMA 3 is usually diagnosed in adulthood. Sam, do you have anything else to add?

Samantha Przyby...:

No, that was pretty much on. And sometimes they go by milestones too. Like I was able to walk as a child and I wasn't diagnosed until I was about six.

Erin Pieper:

Awesome. Well, thank you ladies for answering that.

Mindy Henderson:

Absolutely. Happy to. So Erin, yes, tell us about your book and when does it come out?

Erin Pieper:

Yes, my book is called Dismantling the Disability. It comes out February 22nd. So it's pretty much my life from birth up until present day. So I talk a lot about FA and what it was like when I wasn't diagnosed yet. And then when I was starting to feel like something was off, then going through the process of doctors and

then diagnosis. And then pregnancy, being a mom and just mixing all that chaos together.

Mindy Henderson: Yes. Indeed. Well, it sounds like it's going to be a great book and probably a great help and comfort to some of the other people out there who may be dealing with FA. So I think that's fantastic. And like I said, we'll put a link to it in the show notes. And I am just so honored to have had both of you here today. This has been such a fun conversation for me to have, and I hope that everyone who's listening, had a good time listening to us. And I really just appreciate both of you sharing yourself and your private journeys in the interest of hopefully helping someone who may be listening. So thank you for that.

Mindy Henderson: Thank you for listening. For more information about the guests you heard from today, go check them out at [MDA.org/podcast](https://mda.org/podcast). And to learn more about the Muscular Dystrophy Association, the services we provide, how you can get involved and to subscribe to Quest Magazine or to Quest Newsletter, please go to [MDA.org/quest](https://mda.org/quest). If you enjoyed this episode, we'd be grateful if you'd leave a review, go ahead and hit that subscribe button so we can keep bringing you great content and maybe, share it with a friend or two. Thanks everyone. Until next time, go be the light we all need in this world.