# Jenessa

Jenessa, mom of Zachary (age 15), Alex (age 12) and Zoey (age 9). Alex has SMA-Type 1.



**Jenessa:** So when Alex was born, he was fine, he was perfectly healthy as far as I knew, it's a genetic disease. So seemed his Apgar scores, according to the doctor, were fantastic and everything was fine. But around four months old, I noticed he didn't move around a lot, like babies usually move their arms and legs a lot.

And he never had a strong cry and he didn't seem to be holding up his head as well as he was when he was born. So I started questioning and actually we went to the doctor for his -- it must have been his four-month's check-up and the doctor gave him shots and he didn't move his legs. And his chest was also, they call it pigeon chest, so it was kind of pointy because his lungs were never able to fully expand and kind of flattened out the chest. So there were some signs there that something wasn't quite right. When he was diagnosed -- when he was finally diagnosed, he got really sick and that's the whole kind of story in itself how we got him to Children's. But when Children's diagnosed him, they told us it was usually diagnosed in adolescent children that usually the patient deteriorates to a point where they die. So he wasn't expected to -- we're told he wouldn't live till his second birthday.

And so I mean, I went into the room for the diagnosis because I'm an attorney and there's nothing we can't fix, right? So with my notebook and my pen and okay, let's find out what's wrong and what are we going to do to fix it and let's go, we're going to do this. And then when they gave us the news, it was just beyond what I could have even imagined. So it was devastating and I just cried and cried and so did my husband at the time, Alex's dad. And he -- I remember him just telling everyone because there's a whole team of people, there's always a team at Children's which is wonderful but there was also like -- I don't know, it seemed like there were 10/12 people in the room at the time. So he -- I just asked them all to leave. So we just cried together for a little while.

It was like, you're so happy somebody finally realized something's wrong with your baby and now, maybe we can fix it. But on the other hand, it's like no, no, no, it's not that bad, like this is too much, he's not that sick.

And it was just a devastating time, it was really hard to think about your baby being that sick and that there's no way to fix it.

# I was scared of losing him. I was scared of him not have a quality of life. https://youtu.be/B5ocL8wLf9E

Jenessa: I was scared of losing him. I was scared of him not having the quality of life that you want them to have. I mean you have so many hopes and dreams for your children that I don't think that we ever really process until you get that diagnosis. And every milestone that your child doesn't make whether it's because of their disability or after they passed, it just never seems to go away. Alex just graduated from sixth grade and it was very emotional because I never thought we'd be here, never thought I'd get that opportunity to see him not walk but get wheeled across the stage, so to speak, and get greeted by the principal and all the teachers and given his certificate.



**Jenessa:** Initially when I thought of a trach when they talked to me about the trach, they said, in the future, you would have to decide whether not to trach your child and I'm thinking, no. After seeing that little girl and the thought of -- the way I thought of it at that point was cutting a hole in my son's throat, no. There's no -- there's no way. And when he was 11 months old, he kept getting sick, he was on the BiPAP and we kept landing back in the hospital. And the -- in February, which wasn't that long later, they said they tried to extubate him, take him of the vent and they were unsuccessful. And they said, you have to make a decision, are we going to let him go and do comfort care or do you want to trach him and put him on a vent? So I didn't know what to do, I didn't know how to answer that question.

Because my no from before was no longer on the table because losing my son, letting him go, I didn't want to do that, I didn't want to do that. So they were both bad choices. So I thanked God, I had my faith because I prayed every night for five days, I said, God, you have to make this decision, I cannot make this decision. My husband at the time -- Alex's dad said, whatever you decide, I will support you which is nice in a way but also not terribly helpful. So I prayed, I said God, you have to make this decision, I don't want to let him go but what I really want is what's best for him and I don't know what that is. So in every night that I said those words, I heard in my head, get the trach. And I just figured that's just my unconscious mind telling me what I want to hear. So it was five days and I remember the fifth night, it was more like get the trach.

And so then I was like, I'm standing there, like I started walking around the hospital and every once in a while, I asks someone like a nurse or someone, I'm like, does your subconscious mind yell at you? And most people said no, one person I remember said yes. I'm like, I really don't think your subconscious mind yells at you. I think God just yelled at me because I am not listening. He's saying the same thing over and over, get the trach, get the trach and I'm just going, that's just me because I don't want to let him go. So after I got yelled at, I went back and I told the nurses I'm ready for the PACT team, sat down with them and I said we're going to get the trach. So we did and afterwards, I was so grateful that we had gotten the trach because Alex had been so weak and he was always struggling and the breathing was just hard. And after he was put on the vent, he was so much stronger in so many other ways because he didn't have to struggle to breath so much.

And I remember a few years ago because we were living in this house, so Zoey had already been born, so it may have been five years ago, six years ago. I was walking through Alex's room and he'd been sick for a while and I remember thinking to myself, I didn't say anything, he didn't have a nurse that day, I was his nurse and I was walking through his room thinking, did I really do what was best for him? And I immediately heard the voice say, you didn't make that decision. And so I immediately looked up and said that's right, I didn't. So I didn't have that guilt that did I do -- it's so hard to make life and death decisions for your child, so hard to do that.

# I did not want to isolate him. He loves school.

https://youtu.be/tYYCb0ek6WQ

**Jenessa:** Jay and I -- Alex's dad and I, our goal is to have Alex's life as normal as possible. We want him to experience as much of life as possible even if in doing so that may shorten his life.

I know there are some moms with very sick children who don't want them to go to school because they're afraid they'll get sick, which is very legitimate. I don't discredit them or judge them in anyway. I mean I get it. But I just -- Jay and I just strongly felt that Alex needed to be in school, he loves to be around children, I did not want to isolate him. And he went to that school for three years for preschool because once they're three, they come out of early intervention and so he was three, four and five in preschool there and they've been amazing in Marion. I mean he just graduated from the elementary school, so he was there for eight or nine years and with essentially, almost all the same kids. So they really got to know him and in preschool, we brought in like pieces of his vent tubing and stuff because small children are very curious and they want to touch things and what is that and why is that and they have questions.

And so they were able to do all of that with the kids and let them handle thing and okay, but when Alex comes in, you can't pull on his tubing, you can't touch it. And so I mean they -- and they all grew up with him. So it was amazing in sixth grade, I mean even in third grade but in sixth grade, every once in a while Jay and I will be his nurse and we go to school with him. So you're sitting in the back of the classroom until he needs to be suctioned or he need something and you turn on the suction to suction Alex which disturbs a lot of people. We've been in theatres and people find it disturbing. The kids don't even flinch, no one looks over, everyone --

they just don't even hear it anymore. They just stay focused on whatever it is they're doing. So it's really been a great experience

# I felt like I had a clock ticking down in my head.

https://youtu.be/kvO6D0nlYYY

Jenessa: I remember when he was about a year and a half old, so he had already been trached but they had given us the diagnosis that as of two years old, that's kind of like his deadline. I remember just getting upset randomly and I'm like, what is wrong with me? And I realized that I felt like I had like a clock ticking down in my head like, oh no, I only have six months left, I only have five months left. So I ended up emailing the neurologist and I said, okay, when you gave me the diagnosis or when we got the diagnosis, this is what was said. Now that he's been trached and he's on a vent, does that change that diagnosis? And he said, yes. He said, now that he's trached and on a vent, he could live a very long time. And that's where I left it. My cousin asked me, she said, well, what's a very long time? I said, I don't want to know.

I don't want to know what his idea of a very long time is because then, I'm going to have that clock ticking down again and be worried and stressed and just like any of us, we should be trying to enjoy every day that we have because none of us know when our time will be up. So --

**Jenessa:** I don't often think about how long I have accept when -- I often feel like I fall short as a mom which get me emotional too. Because I work full-time, I have my own business and then of course with three children, you're always running here and there and everywhere with this one and that one and it's easy to throw the 15-year-old and the nine-year-old in the car and go do groceries or go do this or go do that. And at least you have, maybe not quality time with them to do that but you've got quantity.

And I don't get to do that with Alex. It would be very difficult to do that with Alex and I know he would not appreciate it because what kid likes to go grocery shopping and those errands and those types of things. But oftentimes, I don't feel like I am able to give him enough time and now that I'm divorced, it's -- I have like half time with my two kids without the disability, Alex is here 24/7 except when his dad takes them out. So it's just -- it's hard to balance work and family and when you're at work, family and a child with a lot of medical issues makes that balancing act that much more difficult.

# I wonder if I project my own feelings on to him

https://youtu.be/qzi9rpz3oPE

Jenessa: I also wonder sometimes if I project my own feelings on to him like we can do with our children. And because he can't talk and say, mommy, I don't want you to leave or why are you going there again? Or when are you going to read to me? He can't say those things, so sometimes if he seems upset, I'll ask him, are you upset that mommy is not going to be home tonight? And he'll often look at me for, yes and it's devastating. Because for a child, they don't see the need for you to have or need anything, you're a mom, you can do anything and why can't you just stay with me?

So it's hard and I wonder sometimes if I'm planting that idea in his head by asking him that question but with Alex, you have to kind of probe and why are you upset and well, I was just talking about leaving, so is that why you're upset? Yesterday he got upset when we were talking about his father going on vacation to New Jersey with the other two children and he started crying and I didn't want to ask the question because I was afraid of the answer. And he said that he was upset that he wasn't going.

# When he wants to do something, you just want to move heaven and earth.

https://youtu.be/z1mWuBxURSE

**Jenessa:** so I decided to take him to Washington DC this past April which I haven't done a lot since I got divorced with the kids because to be a single mom, going out into the world without having that other partner with you to support you, was just really scary to me. But I did have a nurse, I couldn't have done it without the nurse. And we went for -- I think we went for like five days. We drove down and we stopped halfway there and spent the night so that Alex could get out of his chair and I had contacted another mom who does a lot of -- I don't believe her child has SMA but he's in a wheel chair and he can't move himself. So when they do trips, she's been doing a lot of trips and one of the Children's Hospital doctors referred me to her.

So we discussed the different strategies to try to make this work and make it work for your child. And so that's what we did, we stopped halfway down and stayed the night and then did the other like three hours, three and half hours. So it turned out to be a great trip, it was exhausting, it was exhausting. He really wanted to go to the White House, so Senator Warren's office was able to even though I contacted them, I think, six weeks before and they didn't have any regular tickets left they said but they had -- they were each given like special tickets for someone special. And after hearing Alex's story, they wanted to give the tickets to Alex. So we went to the White House but we had to get up at 4:00 o'clock in the morning to start getting Alex ready because his care takes an hour and a half or so and then we drove to the subway and then we took this train in and

then we had to find the White House and then we had to be there before 8:00 a.m. So it was a long day.

And then, that night we drove our halfway home and stopped at a hotel and Alex had not been in the pool yet, Alex loves to go swimming. He can move a lot more in the pool, so he can move his arms and his legs and the nurses are very nervous with him having the trach. But he's been in the pool many times at this point and so he wanted to go in the pool that Tuesday night and that's when we had gotten up at 4:00 a.m. and the nurse and I were like so tired. I actually told the guy on check-in that we needed a refrigerator for our room and it was actually after I checked in, I had come back to move the van. So I said we needed a refrigerator for I think it was room 522, and he was like okay no problem and then I went into the elevator and I pressed the button for two, and I went -- we're not in 522, we're in like 252 or whatever it was. So I had to get -- I got to the room, called downstairs and I said I just ordered an elevator for room -- and then I went, an elevator? No, a refrigerator, I ordered a refrigerator.

We're exhausted but Alex wanted to go swimming. So we pulled out our last resource of energy and we brought him down to the pool and we went swimming. So it was -- and it's just so rewarding when you can do that for him like, when he asks to do something you just want to move heaven and earth to make it happen.

**Interviewer:** And you will always know that you did that, right?

**Jenessa:** Yeah. I'll probably be 95-years-old telling the story, you know. It's one of those things I'll never forget.

# Moving through the initial scariness, you can be trained.

https://youtu.be/FE4W3NCKfLE

**Jenessa:** I think the whole concept of -- well, to me like I said in my mind, it was cutting a hole in my son's throat and that was just horrifying to me. That kind of overshadowed everything for me. So it's almost like you've taken so much information and then anything extra just kind of bounces off the walls because you don't have any more room to fit anything. I know that the PACT team was available to answer any and all the questions that I had. He had been on the BiPAP, so I knew what it was like to move him around with tubes.

It was explained to me that the trach can't come out, it does get pulled out, it did get pulled out many times and they explained what you would do to put it back in, which is kind if what I did. It was always a little scary if it pulled out, I wanted it back in immediately and they wanted you to -- he has a cuff on his -- and I -- they said you should take the cuff down and then you put it back in, you arch his -- pull his shoulders up and slide it back in. I never took the cuff down, it just -- it had to go back in, you would put slight pleasure and it will just pop right back in and he was good. So I think just the whole scariness of it and whether or not is this what's best for my

child to kind of overshadow everything. So when I felt like I had that question answered, I was okay, we're doing this, you know.

I do remember probably a month or maybe two months after he was trached, just feeling like, wow, like why didn't I want to do this sooner? Sometimes, we don't do things out of fear and then we find out, oh, that was the best thing to do all along, I wish I had done it sooner. So he was burning so many calories trying to breathe, he was using up so much energy breathing that he didn't have the ability or the energy to enjoy other things.

We did have one family that came to our house to meet Alex because they were struggling with the question of whether or not to trach their daughter.

And I don't really remember their visits but when I heard that she had passed, I emailed the family through Families of SMA which is now Cure SMA and just expressed my sympathies with the parent who's pretty much on the same boat. And I think it was the dad who wrote me back and said I don't know if you remember but we came to visit you and Alex in deciding whether or not we wanted to trach our daughter. And because of you, we had seven more years with our daughter than we would have had. So that was an amazing feeling because I think people are afraid, they want what's best for their child, they're afraid that they won't be able to provide that. And you think, well, a nurse could do it, a doctor could do it, they're trained but you can be trained to take care of your kid too and it's not as complicated as it seems.

When you get right down to it, you do what your kid needs.

# You can still find a place for the vent and do fun things.

https://youtu.be/QV-rar0Ws2q

**Jenessa:** Last year, he went on the giant swing, this year he went on the zipline. When he was little, he went on a four-wheeler, we have friends in Mendon who have a four-wheeler and we put the vent in the back, we put the suction on the front, our friend was driving it and he had his baby girl. Yeah, I think it was a baby girl at the time in like a little holster on his chest and then I sat holding Alex behind him. And so he had that experience of being on a four-wheeler and we're just on the street going 15 miles an hour, nothing big but he's been on a four-wheeler. His dad Jay said, at one point, that he was going to take him sledding and I think there's a big difference between moms and dads in so many ways but in terms of your children, moms are more conservative, oh don't do that, you're going to get hurt.

Dads are like, go ahead, go ahead, you may fall down but you'll be fine. So they're more liberal or lenient and go do things, go do something and moms are a little more careful. So I think it's good that you have that balance but I also feel like as the mom, I have the mom card and if I don't think it's going to be safe, I'm going to pull the mom card. So he said he was going to take him sledding and I'm like, I don't think so. I'm thinking, when I was little, we went to the golf course and I remember people getting taken out of there in ambulances, they went into the trees with this, that and you go so fast and it's fun. But as an adult, I realized how dangerous that is now. And so

he's called me granny a couple of times but he said he was going to take him to Taber where they have this like very small hill and then it's the football field for like -- I don't know, quarter a mile or something, it's flat. So he videotaped it or was the nurse videoing it, I don't know.

But you put him in the sled and he is lying down and he's got the vent between his legs and they sent him down the hill and you can hear the nurse going, oh my god! Oh my god! Oh my god! But -- and he liked it, he loved going sledding. And then I think it was last year the nurse came to me and she said, I don't think I can do it Gen. He wants to take him, he said he's going to take him on a raft or a kayak on the ocean. Anyway, no, he's not. No, that's not going to happen. And then when I calmed down a little bit, I said, let's think about this, this is Jay, he doesn't want to hurt his child, I know that, so what is he thinking? His family has a house on the ocean like a beach house, so maybe he's talking about like putting him in a raft like on this -- pretty much on the shore, six inches of water or something and he's in the water, he's on the ocean. So I called him and said, okay, so I think the kayak's out, that's a little too tippy but are you talking about putting him in a raft like near the shore and you're just standing there with him?

And he's like, yes, granny. I'm like, okay, just checking. Had to know that, had to ask that question for my own peace of mind but he's done so many things like that. And his dad's taken him on a Go-kart. The owner of the Go-kart place would clear out the track and I've got pictures, Alex is kind of slumped against his dad and they go around the track in the Go-kart. So you can find a place for the vent, you can find a place for the suction and you can still do things and it's fun. It's good for him.

# You have to try to do what's best for all your children.

https://youtu.be/gRe6hLHavxo

**Jenessa:** If you told me I only had till October 1<sup>st</sup>, my world would stop and everything would be Alex, you know. what are we going to do, but none of us have that timeline and so, you have to live your life and you have to work and you have to juggle everything, and try to do what's best for all your children. I know that Zackary often takes a backseat, he's the oldest, to Alex because of his needs and Zoey because she's younger, so -- but Zoey also often has to take a backseat to Alex because if he has medical needs, that comes first.

So, I think that they're more empathetic kids, they're more understanding than a kid who didn't have that situation. And they're both very good, I mean, Zack's at a point where he can take care of Alex, he can suction Alex. I wouldn't leave him alone with his brother because I don't want him to ever have something, god forbid, something happens that he would have that on his shoulders that it was because I didn't do something or because I did something. But I like to teach them -- I know Zoey even -- she's going to be nine, she wants to be able to suction him, I let her suction his mouth, I don't think she suctioned his tracheae, I'm not ready for that. But she's very mature for her age, so maybe this year will be the year.

# We've had some scary moments with the trach

https://youtu.be/jkpvWRzLQp4

**Jenessa:** We've had a DNR for Alex for a long time, mostly because he's so frail, like his bones are so frail. When you don't use them, they're so thin and brittle that if you do chest compressions on Alex, you're going to break all of his ribs, you're going to puncture his lungs, and I'm just like no, no, no, no, you could've caused him a lot of pain unnecessarily. If his heart stops, then let him go because that works, so if that stops working we need to let him go. If he has a problem with his breathing, well he's already on a vent, so you suction him or do whatever and -- I've had a couple of really scary moments with him. This one time, I thought he was gone, he was grey and I kind of came up shortly after the nurse called me and I got downstairs and I saw him unconscious and grey and I was like oh my god, this is it.

And then I went no, we need to do the work and then see what happens. So I was able to figure out that his trach had gotten pulled out. So, his trach was here and he has sponges to soak up some of the extra secretion and so that was covering it. So, the nurse couldn't figure out what was wrong, so I immediately got the ambu, I don't know why she didn't. I think she might have been exhausted and not thinking clearly. I got the imbue and as soon as I put that on him, I could hear all the air coming out so I was able to get the trach back in, I intubated him and he came back, he pinged back up and I mean, your heart takes all of your oxygen at that point. So, when your skin starts turning -- your heart's still okay but it was scary, very scary. So, there have been times that we've had little scares here and there, and it's usually -- there was one time with my mother when Alex's was little and he started having breathing issues in the car.

And I didn't know if it was because it was too hot in the van when we were going to my aunts for a birthday party or something, so I grabbed him, at the time he was on the second floor when we lived in New Bedford, ran him up the stairs, fell at the top of the stairs with him. There was a bookcase though, I hit my nose and I dropped Alex, thank god, he's like a drunk, so he didn't seem to get hurt at all. Got him in bed and that's when I realized the tubing had come undone from the vent but it was so early on that you don't always -- okay, what is it and then I couldn't figure it out because I tried too quickly, I couldn't figure it out trying to run him upstairs so I could use the equipment upstairs, maybe as a plug, I don't know what's going on. It was just as simple as putting that back in, ambued him a few times and then he was fine. My mother had already called 911. So by the time the EMT's usually get here when we have crisis, the crisis has passed and then I'm a mess because I'm usually okay until the crisis has passed and then I have my meltdown.

So then, I'm like hyperventilating and sobbing and they're like it's okay, he's fine, he's fine, and I'm like he wasn't fine two minutes ago but -- so, you know, you become -- I mean, it's something that you would do for your child who wasn't sick, you know. You call 911 if you find them unconscious on the grass, they fell or something and you call 911, you do what you can but -- yeah, so we've had some scary moments.

# He's doing great, he's fantastic, even as his normal is terrible.

https://youtu.be/0PcjvmklH-A

**Jenessa:** I still worry on occasion about losing him but for the most part, he's so stable and he's been so healthy. He's doing great, he's fantastic but he's not -- but his normal is terrible, you know what I mean? So, he can't breathe on his own, that's terrible, he needs nurses to help assist him to make him fantastic. That's why he's fantastic, he has fantastic nursing coverage, his parents know how to take care of him very well, he's got a great environment, a lot of love and I think that's the primary ingredient for your child to happy, is just to love them and spend time with them and do things with them.

# Deciding to do the spinal surgery

https://youtu.be/9d Mw3tA2BY

**Jenessa:** So, his spine -- it's been at the same percentage for many years and I think all of a sudden, he went through growth spurt and he went from like, I don't know 38 percent curvature to like 80 something curvature and we had a new orthopedic as a part of the SMA clinic and he suggested it and you know, it's a huge surgery. So, I was nervous about doing it, we talked about the pros and cons of doing it.

And ultimately, we just felt like this is what's going to be best for Alex. It was at the point where his body jacket wasn't keeping him comfortable and so if he wasn't going to be comfortable then we had to do something about that. And so, we decided to go forward with the back surgery, they told me they would put eight pins in his head and then put them in traction for five weeks, I think it was supposed to be three weeks originally and it ended up being five weeks. And that they put like a weight on it, and you have the halo and just try to stretch out the spine as much as possible before you put the rods in because you want to make the spine as straight as possible before you put the steel rods in. I'm like okay, I get that. I'm thinking pins, okay, no big deal, pins are fine. And then when he came out of that initial surgery, that -- and it's like a five-minute thing where they put the bolts in, okay. They're really bolts.

I mean, they're not huge but when you see them going through your son's skull, you're going oh my god, he has like Frankenstein bolts in his head but I always look at his heart rate and his heart rate's good, which means he's comfortable, so it's not hurting him. It hurts me to look at it, but it's not hurting him and that's what I have to focus on. Over the course of those five weeks that we were at Franciscan going back and forth, they straightened him from the 90-degree curve to a 50 percent curve. And then the surgery itself is a

delicate surgery, it's time consuming but he was able to get Alex's spine from that 50 percent curve when we were admitted the night before to a zero percent curve. So, he's completely straightened out, completely straight which is amazing. And he doesn't have to wear that body jacket anymore which is hot and bulky and it was tough to put on and tough for him to deal with, I'm sure.

And it took a while for that, the incision is like from maybe the bottom of his neck like all the way down to his tailbone and so, there were times where that was still like oozing and really like, should this be okay? Is it infected? We went up a few times to have them look at it, sent them pictures of things, is this right? But yeah, he's doing phenomenal, so I mean, it took some time for that to completely heal, I mean it's a huge surgery. I'm so happy we did this, you know, it was scary but now, I mean he sits up so straight, he's so much more comfortable, before he was like this and they said if you want to know how it is to breathe with scoliosis especially when you get really far over,

If you bend forward and try to take a deep breath, you can't because you're like crushing your chest, that's how it feels for them to try to breathe. So, now he can -- I felt afterwards that respiratorally he seems so much better, like it was like things had opened up. You know you have the -- the storm has passed, we went through it and wow, this was really a good thing.

This is the gift that Alex gives us, that he reminds us every day to be grateful that we can breathe on our own, I mean how simple is that that we don't -- we take that for granted, I mean, who doesn't? But when you know Alex and you know he can't, you're like this is something I should be grateful for, that I can breathe on my own.



**Jenessa:** And just to be stuck in -- I mean it's a raised ranch, so the lower level isn't as bright as the upper level of the house and to me, it just seemed so sad to be stuck. Alex can't move himself around, his brain is fine so he knows what's going on and he understands everything but he can't communicate. So he doesn't have his voice, he has sounds that he can make but he doesn't have words. And at this point, since a few months ago, he has basically no movement that you can see. I know with physical therapy, he -- and even sometimes I'll lay down with him to read and I can feel him contracting his leg muscle, so I can feel him moving.

But he had some movement in his thumb and he would tap on my arm. And a few months ago and he'd use switches to activate toys or things that way. So up until a few months ago, one of the nurses said, he doesn't have that movement in his thumb anymore and I'm thinking, that can't be right, of course he's got that movement. And sure enough he didn't have it anymore. And it was sad because we had just gotten -- what is it? It's a remote control car, he had gotten this big remote control like 4X4 Jeep for Christmas and we finally got it, made it to a switch toy. And so he'd used it like two or three times and we're using it as like an incentive for him at school to do his work and then he got to play with the toy. So I think he got to use it two or three times before he lost that movement. So it was like another loss, so it was sad.

And then when we called -- I think one of the nurses called the doctors at Children's just to let them know that he had lost that and so he said, well, it's just a progression of the disease which we don't know a lot about because Alex is the oldest child with SMA in our clinic. So I mean, at first that really upset me and I was like, wait, wait, I know a 15-year-old with SMA type 1, I know an 18-year-old with SMA type 1. So he's not the oldest SMA patient out there but in that particular clinic. He's the oldest kid that they have. So they're still learning, they're still learning about the disease and the progression of the disease.

# I'm going to keep moving forward.

https://youtu.be/RddXg4dMoTk

**Jenessa:** So I'm going to enjoy what I have today and tomorrow and plan for next week and keep moving forward. There's a movie called Meet The Robinsons and his mantra is keep moving forward and that comes up in my head so many times, just keep moving forward because some days are harder than others and you just have to -- okay.

Sometimes, you just focus on the moment, I like to say like, can I put the blinders on some days? I can't handle everything, I can't handle that the dining room kitchen table needs to be cleaned off or there's dishes and laundry and okay, I have to take care of Alex, I have to get Zoey ready for camp, I have to -- and just focus on the immediate what's in front of you. And sometimes it's just an hour, what do I have to do now, this minute and that's what I do. So, sometimes I don't think about what's going on tomorrow until I'm in bed at night going, okay, what do I have to worry about tomorrow? So, some days are like that, and other days are easier, I mean you can think beyond today or tomorrow.



Jenessa: I still pray every night and talk to people about my faith and I listen to Christian music like almost nonstop from the time I get into the car, it's just that constant reminder that don't fix your eyes on the problem, fix your eyes on god, he's got a plan, he knows what the plan is. It's like -- there was a story about these people who had died and they went to heaven and they had these like afghans and look how beautiful mine is, look how beautiful mine is and this one woman, hers was like had all kinds of holes in it and it looks like it was a mess. But if you look at it from afar, so it's like all the problems in her life and it was a mess but you look at it from afar, and it was the face of Jesus. It's like that's what you have to remember.

God has a plan and in the end -- like we don't know what the plan is, we don't get it but someday we will, and someday we'll say oh, that's -- you know, I had to have that experience so that I

could help that person or that person helped me at that point and you know, it's just like this beautiful tapestry that gets woven together and the Christian music reminds me that he has a plan, his plan is good, he does not want to hurt me, that doesn't mean that bad things won't happen to me but he'll turn it to good. You know, like having Alex's diagnosis, that's not a good thing, it's not something anybody wants to have, it's not a club anyone wants to be in. But once you're in it, you learn to deal with it and you're like okay, this isn't so bad, there's other people, good people -- and how is this going to be a good thing and start to look at the silver lining. Everything has a silver lining as devastating as sometimes things are for people. When you have some --

When you can look at it in hindsight, you can say oh, I can see that our family wasn't close and then, we have this devastating thing happen and boy, did that bring us together. Or I was so focused on all these things that didn't really matter and then this happened and it really lasered me in on what was important. So, I think everything's about choices, you can choose to look at things and focus on their negative which some days I do and I can't always be positive but I think the Christian music helps me to remember, focus on the positive. This too will pass, you know, it might last for today or tomorrow or the next month but it will pass. And what am I going to learn, and how am I going to grow, how am I going to get stronger through this? And sometimes you just say you know what God, I think I'm strong enough, like I don't want anymore, okay, I'm good. Please, you might think I'm stronger but I'm not, like enough please. So, it's --

I think the Christian music just really helps me to stay balanced mentally, emotionally.



Jenessa: One other thing that I want parents to know is to be empowered. Just because this person's a doctor, if he tells you something that you don't agree with, you don't think he's right, move on, go and see someone else. As a parent, I think you have an innate sense of what's best for your child and what's going on with your child. So the doctor that told me in September there was nothing wrong with Alex, there is something wrong with this kid like big, you know. I didn't realize how huge but it wasn't just that he was month delayed and so, being empowered that -- don't say oh, he's the doctor, he knows, no. Perhaps he doesn't know because they're just like us, they put their pants on the same way, they don't know everything, just like no lawyer knows everything, no doctor knows everything, no nurse knows everything.

And we should all be humble enough to know that we don't know everything and therefore we need to seek guidance from others. And if I ask you a question and I don't get the answer or I'm not comfortable with the answer, I'm going to ask someone else. You know, be empowered to do that, that's your child, leave no stone unturned. And don't worry about offending people because

if your doctor's going to be offended -- I think the doctors nowadays are much more open to a second opinion.

I think sometimes we worry oh is this going to affect the care my child gets, no these people are there because they care. And especially Children's Hospital, I think it's -- for your own peace of mind, you need to know that yes, I asked every question or I feel like even saying I feel like something is still missing, we haven't covered everything. I don't know what to ask you, but is there another task or is there something else that we should be doing.



#### **FINDING SUPPORT**

Reach out to other families, they're on the front line every day. https://youtu.be/9ycEg8a3Rqg

**Jenessa:** See if you can reach out to other families because I think other families are very open to talking to you about their experience. Alex has seizures and that's not normal for SMA, it's not a part of SMA, I should say

And that was the scary part, we thought we were going to lose him, he was seizing for like 10 to 12 hours. So, just learning things from families because they're like the ground troops, they're on the front line every day, they're experiencing things that the doctors are not going to necessarily know or see. So, don't be afraid to do that and if you don't want to talk to somebody on the phone, you could send them an email so you don't have to necessarily get that person -- you don't have to meet for coffee, if you want to meet for coffee, then you ask them to meet for coffee but do what's on your comfort level. And I think families are just very open to talking with others and helping others.



**Zack:** Well, for me, it's like the attention thing -- for me, I don't mind not getting a lot of attention, at some point I actually enjoy not having a lot of attention and I understand that he needs most of the attention, so you just have to deal with that. You can't really complain or anything because he needs the attention, it's not like he wants it and he gets it, he needs it.

**Zoey:** Yeah, like what mommy said, like we get to see it a lot because we know Alex needs something so we're used to that because he needs it and for siblings that don't have that -- they might get like I'm not getting any attention, like what's happening.

**Interviewer**: And so what you would say to them is --

**Zoey:** That you have to get used to it, they need it because they have to --

**Interviewer**: They can't do it themselves. That's very wise and very true and also very loving. It's not always easy to not get the attention you want, even if there's a very good reason for it.

**Zack:** Especially for him.

**Zoey:** Yeah, once at Double H, I tripped and fell and I got a really bad scrape but Alex needed to be suctioned so mommy suctioned him and then she took care of me.

**Zack**: Well, I think being suctioned is a little bit more important than a scrape.

**Zoey:** I know, I was just saying.

**Interviewer**: I know what you meant, you guys are awesome. Do you have a question for them?

**Jenessa:** I don't know, I just feel like to tell them that it's okay to be jealous about Alex, he gets so much attention and it's okay if you're upset like oh my god, I just scraped myself and Alex needs to be suctioned, you know. It's okay to get frustrated sometimes, I mean, you know,it's not always going to feel like sunshine and roses, yay Alex, it's taken care of. But you also -- I mean, you've been doing this longer, Zack.

**Zack**: Yeah, when I was younger, it was probably more difficult because the younger you are, the more attention you need going from baby all the way up and then teenager's kind of like the anti-social years, so I have a man cave so I can just spend all my time in there or working on my cars.

**Zoey:** Yeah. And he said like when you're --

The age of growing up, you don't understand you need attention but someone else is getting it, you don't understand that he needs it.