00;00;06;10 - 00;00;31;27

Autum

I never wanted a doctor to diagnose another kid and be like, You're on your own. I wanted them to be like, Hey, there's another woman here that she knows all the ropes and she will help you because I don't ever, ever, ever want another family to have to hear. There is no hope. We cannot help you. We do not know you're on your own ever again.

00;00;36;04 - 00;00;47;24

Courtney

Welcome to Adjusting the Sales, a podcast for parents, caregivers and service providers for Children with Disabilities. I'm your host, Courtney Ring Staff, and this is my co-host Marlina Danko.

00;00;48;04 - 00;00;51;00

Melina

Hi, everyone. We are so glad you've joined us.

00;00;51;07 - 00;01;21;25

Courtney

Melina is the assistant director of communications and marketing at the Center for Excellence in Disabilities and the project director of the West Virginia Family two Family Health Information Center. I am a licensed social worker in Morgantown, West Virginia, and I've created this podcast to be a platform for parents, caregivers and service providers can come together, exchange information, educate one another, and find support and connection through the relatable topic discussions.

00;01;22;19 - 00;01;31;18

Courtney

We cannot change the direction of the wind or the strength of the storm, but together we can adjust the sails.

00;01;34;05 - 00;02;09;01

Autum

My name is Autumn Johnson and I am the mother of three very beautiful, wonderful children. I have a daughter who is 13. Her name is Adeline, a son who is eight. The name is Alexander and another son who is three years old. And his name is Deborah. Alexander has spinal muscular atrophy. He was perfect at birth. And then slowly he began to show symptoms of some kind of similar to Deborah's showing symptoms of autism spectrum disorder, where it was only a short amount of time before I noticed something was off.

00;02;09;14 - 00;02;40;06

Autum

So those two both have disabilities, and we handle those as best as we can together. That's amazing. Neuromuscular disease. It doesn't involve any of the the heart, the lungs, the brain, none of that. There's SMA zero through four where SMA zero would be very, very rare because those children do not survive. If you are looking at it in the case of severity, it would go as some type one, type two, type three and type four.

00;02;41;21 - 00;02;44;20

Melina

What does a day of caring for Alex medically look like?

00;02;45;08 - 00;03;06;09

Autum

It looks like you don't get a very, very much sleep. Sleep is not on that schedule. It's very up in the air, depending on whether we have nursing and whether we have doctor's appointments and whether we have therapies. And if his siblings go to school or if they're home and how we interact, the way we interact on weekends is not the same way we interact during the day in the way that those things go.

00;03;06;12 - 00;03;28;20

Autum

And just to be completely clear, Alexander runs this house. I may pay the bills, but if he wants to sleep, it's sleep. And if he wants to watch a movie, it's watching a movie. There is no making Alexander do anything he doesn't want to do. We have several different nurses that come to the house, and depending on whether or not they can be here, that changes the way the dynamic of the day.

00;03;28;21 - 00;03;53;03

Autum

I usually get more done, like cleaning wise or work wise when there is a nurse here. Alexander gets a bath every morning and I also wash the dishes. Or do the laundry. But if there's no nurse here, I will be. Alex and Sheldon are the laundry and then the dishes that second. So it all depends on what exactly who exactly is here, what exactly we're doing that day.

00;03;53;03 - 00;04;13;22

Autum

But basically, if we're talking about like the weekend where everybody is here and everybody is home, I have a pull out count. All my kids have their own room. There's a TV in each room, but we have a big TV in the living room. So what we do is on the weekends, because we have an hour Saturday morning and then we have an hour Sunday night, but Saturday night and Sunday morning, we don't have an hour.

00;04;13;22 - 00;04;33;28

Autum

So it's, you know, everybody's tired. So keeping my kids all together helps and keeping them all happy, all all healthy, all see, instead of Deborah is over here and Alex needs this and that. He's in a room doing something when when it's just me and there's no nursing. That is a big help, because she's the one that carries the ventilator.

00;04;33;28 - 00;04;54;02

Autum

When I carry Alex, she's the one that wrangles Deborah, if I have to treat Alexander in an emergency, I have to do all the regular mom stuff and then all of the medical mom stuff too. I have to make the dinner and I have to do the laundry and I have to do the bags and I have to, you know, I mean, and then I have to clear the tube and caucuses.

00;04;54;02 - 00;05;25;14

Autum

And those things don't always happen in a smooth way. Like last night, a prime example, I was making dinner and as I was making the sausage, Alexander status and obviously the sausage can burn and it did. It absolutely did. But Alexander's condition is just so like Russian roulette that every day is different in the aspect of if he doesn't feel good, we're not doing this.

00;05;25;15 - 00;05;47;14

Autum

If he feels great, then we can do this. And a day to day, if I have honors, I'm I'm more free, but I don't necessarily do anything. I usually get like the housework done when I have nursing or I go grocery shopping or, you know, I mean, like just do the regular things that you would do if you had a non-medical if I don't get.

00;05;48;25 - 00;05;50;17

Courtney

What does communication with him look like?

00;05;51;13 - 00;06;09;08

Autum

One of the things Alex likes to do when people will talk to him, I just when people try to talk to him, he will look directly at me and then roll his eyes in the back of his head and hold them there. And I'm like, you have to not do that because people will think you are more disabled than you actually are.

00;06;10;01 - 00;06;41;20

Autum

I was like, I have to actively tell people that there is nothing wrong with you mentally. Alex likes to mess with people and I have to be like, Stop that. You know, cognitively he's one of the smartest little eight year old boys I've ever met, but he can't verbalize that. And a lot of the time when I describe the communication that me and Alexander have or that Alex and Addy have, because Addy does have the same type of communication with Alex that I do, it's a learned over time that you don't have to actually say anything to.

00;06;41;21 - 00;07;01;15

Autum

Everybody has a friend that they can just look across the room and like make facial expressions at and you can have a whole conversation that way. And that's pretty much how we conversate with Alex. One one eyebrow being raised and, you know, to something means that that's what he wants to eyebrows being raised and like a block away means he doesn't want that at all.

00;07;01;23 - 00;07;24;00

Autum

There are different like little facial expressions that he makes that indicate to people because so there are some people that when I have a conversation with Alexander, they're like, how do you know that that's what he wants? And I'm like, eight years of trying to figure it out. Eight years of being involved and being like, Okay. And then sometimes I'll find myself making faces myself that like not being verbal with him, but having a whole conversation with just our faces.

00;07;24;24 - 00;07;48;17

Autum

But that's yeah, that's pretty much what communication looks like. I'm working on getting an eye gaze for him because we had one before and then it broke. It's been a we all of the time trying to get it for him. Most of the time the people that we have to go through don't want to do it. The way that works for him uses Xigaze laying down and they want to test him sitting up in a chair.

00;07;48;24 - 00;08;09;19

Autum

And I always say it's like asking a fish to climb a tree. They can't do it, but that fish can swim. If you put that fish and water that bush can swim. Alex is that fish he needs to be in water. So if you are sitting him up and he can't actively use the machine and you're like, okay, we're writing it off.

00;08;09;19 - 00;08;34;03

Autum

He can't use it when he can use it lying down. You're not helping him have a better quality of life, and that kind of makes me angry a little bit. We're doctors or therapists or somebody, or even with equipment like wheelchairs or I mean, they don't do it in a way that is helpful to Alex. They do it in this like cookie cutter fitness box way, and that just doesn't work for us a lot of the time.

00;08;34;03 - 00;08;37;06

Autum

A lot of time. It's just not viable for him.

00;08;38;16 - 00;08;48;11

Courtney

And that statement speaks on your level of advocacy for him. And that leads me to my next question about his medication.

00;08;48;11 - 00;09;11;08

Autum

Spinraza He's actually not on Spinraza anymore. It is the spine throughout this whole medication thing has been a ride. Let me tell you, from the moment he was diagnosed, I like the second I knew what he had. I was on the Internet. I was going through I was reading things, you know, I mean, making sure that I absorbed as much information as I possibly could because I believe that knowledge is power.

00;09;11;08 - 00;09;35;03

Autum

The more I know about this, the better I can help my kid. And I found a clinical study for Spinraza, which was called Nusinersen at the time in Ohio. We were going to LifeFlight them from Ruby to Ohio, this, that and the other, but he contracted RSV, which caused us to have to make a choice. One of the things that I will never forget as an experience that I had with Alexander was making that choice.

00;09;35;25 - 00;09;56;04

Autum

One of the doctors and it's burned in my brain. I will. I will remember to tell that day what this man was wearing when he said this to me. Alexander got asking and they said that we could either watch it and see how it goes, see how he can, you know, if he fights it off, if he's okay, track him and give him the help that he needs.

00;09;56;14 - 00;10;20;16

Autum

But that keeps him out of the trial for the medicine. Or you can wash your hands, clean up him and sign him over to the hospital, which I never even knew was something that you could do with your kid. That was not a choice for me at all. I weighed the the pros and cons. Do I do I see if he can fight me at such a young age with such a devastating condition?

00;10;20;22 - 00;10;51;19

Autum

Or do I give him the help that he needs and legitimately wait it out to see if we make it to when the medicine becomes available? And we did. I was such a nag to this company that they knew me by my first name. It wasn't Miss Johnson. It wasn't ma'am. It was Autumn. When I tell you that I am willing to go be above and beyond to get the help that my kid needs.

00;10;51;23 - 00;11;23;02

Autum

I'm going to tell you the level of crazy I was willing to go to. Biogen was the company that made Spinraza and I wasn't getting the answers that I wanted and I wasn't getting like I was getting the runaround in whole nine yards. So I figured out their emailing process, like how they do their emails for their company, use that to figure out what the CEO's email was, and then sent him a message which I promptly got one back and he was like, all the data, you know, we can do this, that and the other data.

00;11;23;25 - 00;11;45;22

Autum

At the very end of the email, he was like, By the way, how did you get my email? I'm a crazy person. That's how I got it. I figured it out myself, so the information that he gave me was a bunch of blue. We understand that we weren't going to let up, but when Spinraza became available, when the FDA approved it, I have no idea why, but people were like thanking me like I had something to do with it.

00;11;47;12 - 00;12;03;25

Autum

All it was, was I was just being a nag constantly because I would just I would learn what I would learn. And then I would go to the CMA board and I would tell everybody, this is what I learned. I spoke directly to this person. I even screenshotted the email that I got from the CEO and sent that to them.

00;12;03;25 - 00;12;25;10

Autum

Every single thing that and that's what I do with everything that I do is if I learn something, I try to make it useful, I try to use it to help not just my community but other people. Because not all the information that I learn or acquire is some information. Some of it is other information that can help other people that have children with other disabilities that tell you about.

00;12;25;10 - 00;12;38;06

Courtney

Spinraza Yes, Annette told me a lot about your level of advocacy, and I think you sell yourself short saying that you didn't have anything to do with it. Crazy person It takes a level of crazy sometimes.

00;12;38;18 - 00;13;04;06

Autum

I like when I'm told, like when that happened, I was like, yeah, I was like the universe was like, you know, the summit community needs help. I know this crazy lady that happens to be pregnant if we give her kid some, maybe we can get the ball rolling on this. You know what I mean? I was news crews, I was journals, I was every doctor I could get a hold of, every pharmaceutical company, every clinical trial, everything I could possibly do in order to get the help for my kid.

00;13;04;10 - 00;13;33;11

Autum

And then essentially, you know, trickle down to every other kid that has asthma and not only that, I not want to make this. The cure for asthma opens the door for so many other neurologically developmental illnesses like to be cured, like ALS, Duchenne muscular dystrophy, all of these other conditions that are that are similar, like genetically similar to SMA and and and asthma is the closest genetic disorder to being cured.

00;13;34;02 - 00;14;01;25

Autum

The closest one. The second we kick open the door and cure asthma the the flood of capabilities for every other family that doesn't not even remotely have that something that has other genetic content like like that to me is amazing that this one condition that if it in my lifetime is cured can legitimately help other people that don't have it.

00;14;02;21 - 00;14;18;29

Autum

I think that's I think that's that's that's amazing. So I advocate for that very much to the curing a person may not just for the cure for Esmé but the cure for so many other things that are detrimental to you know, families.

00;14;18;29 - 00;14;29;06

Melina

So Autumn, could you share with us, were you successful in finally getting Alex Spinraza and did it help him?

00;14;30;11 - 00;14;55;09

Autum

Yes, it was a fight to the nail, though. I had to go against the insurance company four different times in court. The day that I got this is the funniest thing. It's not funny. It's actually it blows my mind. But to me, I'm like, The funniest thing is that when he was denied for Spinraza, the insurance company said that the reason that he was denied for Spinraza is because he was too sick and it would not help him at all.

00;14;55;13 - 00;15;12;17

Autum

He was too sad. Then that same week we got a denial for 24 hour nursing, and their answer to that was because he was too well for 24 hour nursing. And so when we went to court, I was like, So what is it? Is he too sick to get Spinraza to the point where you guys want to prove that?

00;15;12;26 - 00;15;38;19

Autum

Or is he doing so well that he doesn't need 24 hour nursing because it cannot be both? He's either too sick and needs 24 hour nursing or he's not that sick. He doesn't need 24 hour nursing, but he can get the spinraza fighting tooth and nail for that. I'm telling you, I was denied several times before I found out that Biogen had a low income program legitimately.

00;15;38;19 - 00;16;03;06

Autum

I was calling because just to see if they would give it to me, like I was just like, I don't know what to do. How much money can I do I have to raise? And it was at that time the most expensive drug on the market. Okay. Like millions, like just a ridiculous amount of money. And now Zuma gene, the gene therapy is the most expensive drug on the market for anything because it is gene therapy.

00;16;03;15 - 00;16;31;12

Autum

When when I when I tried to get everything together and it was like, oh, I don't I don't know, I you know, I'm losing hope. There are nights that I would cry thinking that, you know, it was never going to happen for him because these dark insurance companies just didn't want to listen. When I told you, I went from I'm going to pull your heart strings, a court hearing to a fiscal like like a breakdown of like if he gets this medicine, the implications in the future that you guys wouldn't have to pay for.

00;16;32;17 - 00;16;50;02

Autum

I tried every which way to fight the insurance company so that they would pay for this medicine. And they never did until I found out that Biogen had a program and they put me on the program and they said, We just give you the medicine, but we can't pay for the procedure, anything like that. And the procedure was about $10,000.

00;16;50;09 - 00;17;17;17

Autum

So I tried everything I could to raise the money, and I finally raised enough money. But because Ruby was a teaching hospital and Maggie Janes is the most amazing person ever, she found a way because there are three other same families that were coming to Ruby to get their medication. She asked the other families if they would wait because of some kind of loophole that I wouldn't have to pay for the procedure because if they she said, Do you care if there's a student in there?

00;17;17;17 - 00;17;40;15

Autum

And I was like, No, not at all. If there's a student present and it's a teaching thing that they could do that for me. But he had to be the first one to get it like another. Another family couldn't be the first one to get it. And I was like, okay, so Maggie and I knew all the families and all of the families that are in West Virginia all were approved because their child had type two and were were less severe than Alexander.

00;17;40;15 - 00;18;08;10

Autum

So they were all willing to wait so that we could get that every time I think about it, I want to cry because I'm like, that was just amazing. Like to put my family first before your own. You guys were fighting to for the same medicine. We got it taken care of because Maggie Gaines and the other families were amazing and Alex was on Spinraza for about two years before Christie came out, which is an oral medication.

00;18;08;23 - 00;18;31;18

Autum

And it is better for him because he takes it every day. It's better for him to take that every day than for us to pack him up, take him to the hospital every four months to get a spinal injection in his back, because it's not it's invasive. It's not, you know, I mean, we can just give him this medicine that works for him better than the Spinraza did.

00;18;32;24 - 00;18;49;03

Autum

But Spinraza literally saved his life. It stopped the progression of the asthma. And I will forever be thankful for everybody involved in that because it saved my son essentially.

00;18;49;03 - 00;18;50;19

Melina

You should include yourself in that.

00;18;51;28 - 00;19;32;08

Autum

You get crushed. You have us all crying. I don't I don't mean to. I don't mean to. But yeah, no. The experience of getting the spinraza was was a rollercoaster. The day that we got the call that he was going to be capable of receiving, it was one of the happiest days of my life. I bawled for like a week because it I mean, it was just really amazing and it felt like two and a half years of like and I'm talking like legislation in the West Virginian Capital to provide screening for spinal.

00;19;32;11 - 00;19;54;19

Autum

It's like, you know, how like they had the triple screen, they had the quad screen. And in it, when you get an amnio, they test for spinal muscular atrophy. Now in West Virginia. And this was passed a couple of years ago. And I wasn't I wasn't the only person, you know, that had something to do with it. Other estimate, families in West Virginia had a lot to do with it as well because they were capable of actually going to the capital and advocating.

00;19;55;07 - 00;20;12;05

Autum

I was capable of using our our district. Danielle Walker, she came she met Alexander and she fought for us where I couldn't go myself. So when I say that, I will tag somebody in, I mean, if I if I knew, if I can't do it on the tag, somebody in that can do it.

00;20;13;22 - 00;20;22;26

Courtney

It nurses teach you what you needed to know to care for him medically. Or did like your medical teams. Did you just research it yourself?

00;20;23;09 - 00;20;53;02

Autum

I had I had so many scary things happen at the beginning of this that to tell you would sound like a horror movie. Alexander was he was two weeks old, so August 14. And then he was diagnosed with spine muscular atrophy on September ten. And then we didn't leave we didn't come home until November 28 because after he was trained and had a G2, we had to be trained to pick.

00;20;53;02 - 00;21;07;26

Autum

You had multiple different nurses teaching us things. And when you people teach you stuff, they have their own ways of doing it. And so one nurse would show us how to do it their way. And then we would have to present to another nurse that would like sign off on whether or not we knew what we were feeling.

00;21;08;02 - 00;21;25;13

Autum

And sometimes that nurse would be like, No, that's not the right way to do it. And we spent three extra weekends proving that we could take care of Alexander before they would let us bring him home. The way that they made it sound like they're like, Oh, when you train to change the train, which was terrifying at first.

00;21;25;13 - 00;21;44;03

Autum

Now I could probably do it as close, but terrifying at first they were like, Do it quickly or it's going to close up. Had me thinking that it's going to close up instantly. Like if I did a, you know, mean one when if I'd have thought about it for more seconds it for a good long while when I did Trig changes, I was doing them as fast as I possibly could.

00;21;44;10 - 00;22;09;20

Autum

I was a bartender before all of this. Now I'm legitimately medically sound and everything. SMK and Alexander related, pulmonary wise, feeding tube wise. Those things like I have to say the very least to be taught by nurses who I have high regard for, none of them correlated together to be like, okay, this is how we do this. So that we weren't learning eight different ways to do one thing.

00;22;09;28 - 00;22;29;24

Autum

And eventually it got to the point where I just did it the way that I felt the best at doing it. We had the charge nurse come in and I explained to her how frustrating that was. I was like, You have one nurse teach us how to do something and another nurse evaluate us while we're doing it. And those two nurses don't agree.

00;22;30;09 - 00;22;47;23

Autum

We had to find a new apartment because we didn't have room for him in our two bedroom apartment. So we got a three bedroom apartment where we lived and it was a handicapped apartment on the bottom floor that they had to redo for us when we moved in. And then we had to have the Guinea company come and evaluate his room.

00;22;47;23 - 00;23;24;00

Autum

So we had enough plugs and if there's enough space and you know, I mean, stuff like that, it was very tedious and very like downbeat about the whole situation because everybody made me feel like I was in a like I was just don't, I don't know. And it wasn't that I wasn't willing to learn. It was just that when people who have more knowledge than you and are more willing to look down their nose because you don't know what's going on, as opposed to seeing that you don't know what's going on and being like here, let me show you was very frustrating as 99% of the reason I do the doc project is because of

00;23;24;00 - 00;23;42;24

Autum

that, because bedside manner and the way that some of these disciplines talked to me or spoke to me made me feel very inadequate, made me feel like I was not going to get any better at what I was doing. And that's frustrating. And I know that that's just not that's not just me. I know that that's other parents as well.

00;23;42;24 - 00;23;47;29

Courtney

So when in reality, I feel like you should either go to medical school or law school, I can't decide which one.

00;23;48;24 - 00;24;08;26

Autum

I very much try to learn as much as I possibly can so that I can help people and not just not just about, you know, for me, but like autism and, you know, Duchenne muscular dystrophy and anything it looks like like anything. But if I can read it, if I see it and I recognize it and I'm like, okay, I know somebody that has that or I know somebody can benefit from that information.

00;24;09;09 - 00;24;24;20

Autum

I like to share that. That is I love that. That's why I love the CD and I love the one students and all that. I love the ability to help other people that have the same situation as me that makes me so happy because nobody was there to help me. Like not a single person was there to help me.

00;24;24;27 - 00;24;46;14

Autum

Nobody held my hand. Nobody, you know, said, Hey, why don't you sit down? I got this. I know what's going on. I had to learn it all by myself. The diagnosis doctor was like, We don't know very much about it. You're going to go look it up. I was like, Okay. And I did. And I learned as much about it to the point where the pick doctors would give newly diagnosed families my information so that they could get hold of me.

00;24;46;14 - 00;25;06;13

Autum

And I was capable of helping three different newly diagnosed families that had come to Ruby from other states because of their asthma or because they needed that was the only place that they could get the medicine that they needed or the interventions that they needed. Any time that they were diagnosed there, they would give them my information and I was glad to help people that were in the same situation as me.

00;25;08;02 - 00;25;14;06

Melina

Can you talk to us about the I.D waiver and what that process was like for you?

00;25;14;06 - 00;25;31;04

Autum

I was told about the I.D. waiver through birth to three. I had no idea about it. And now every single person that I come in contact with that has a child with a disability, I tell them about the waiver. Alexander was two when we put him on the waiver and there was a waiting list a couple of years back.

00;25;31;11 - 00;25;50;15

Autum

They had some extra funds for the government and they decided to wipe the list clean and make it so that everybody that was on the list could could viably get the waiver. So that was super, super exciting, but it took about two and a half years of waiting. And like at that point in time, Alex, Alex was on the list for two and a half years before the clearance came.

00;25;50;16 - 00;26;05;24

Autum

He probably would have been on for two and a half more years because the last time I called before the clearance came, he was number 143 on the list, and they said that they would clear out the list like 20 to 30 people twice a year. And so that would put Alexander out like two and a half more years.

00;26;05;24 - 00;26;25;17

Autum

So he would have been way older before. I would have had the opportunity to make money taking care of him and the opportunity of therapists that that know him to come in O.T. And and we're currently trying to get a speech therapist to come into the home, but there's not many on the waiver that you got that come into the home.

00;26;25;17 - 00;26;29;15

Autum

So we're working on that.

00;26;29;15 - 00;26;33;20

Melina

So Adam, what are some ways that you have integrated Alex into community activities?

00;26;35;19 - 00;26;57;05

Autum

I used to live in in a apartment complex that had a lot of children and we would bring Alexander out and he would enjoy watching the children play. A lot of the times we would set off fireworks because he loves those moving gave us a lot of benefits, but it took away a lot of the things that we loved about living in the apartment complex.

00;26;57;05 - 00;27;23;06

Autum

Like the community of it. I take Alexander into community events in which I know the people that are there. We took him to the hospital once for a doctor's appointment and like the whole entire waiting room was empty at the time and we were having a lot of trouble with the oxygen tank and the pulse ox and stuff like that and so on.

00;27;23;20 - 00;27;46;07

Autum

The appointment was terrible. It was just a lot of stress that went with it. And then when we came out, the waiting room was full and Alexander's machine, everything was going, you know, and so every single head turned to look and I was having a bad day. Thankfully, my nurse was just so kind, but I was like, You look like you're all staring because he's cute, right?

00;27;46;07 - 00;28;03;15

Autum

That's the reason you're staring. It's because he's cute, right? That's the reason. Because I was just so, like, I'm talking, like, angry tears at this point in time and my nurses, like, yeah, because he's cute. Let's go. Because it was just such a frustrating time and it's adults. It's like kids. I just want to make sure that I'm very clear.

00;28;03;21 - 00;28;23;29

Autum

The people that stare and have faces are adults. Like really kids are even more curious about Alexander than anything else, and I have no problem. Like when we were at the gardens, what we would do is and everybody at the gardens, like, knew Alex. What we would do is I would put him in his chair and I would put chalk on the ground around him.

00;28;23;29 - 00;28;47;18

Autum

And the kids knew that they couldn't get that close to him. Like they had to stay on the outside of the chalk to the point where it became a game. They all had a lot of questions and all of the questions were very innocent. When I think about taking Alexander to communal events, I highly consider the variety and quality of individuals that are going to be there.

00;28;49;01 - 00;29;09;20

Autum

We rented a movie theater for his birthday and had people come and watch Thor for his birthday. So our when we do community events, there is so much that goes into getting Alexander to where he needs to go and so much thought that goes into like who is going to be there and and how they affect Alexander's life in a positive way.

00;29;09;20 - 00;29;29;01

Autum

So we don't just go like willy nilly, like we're just going to take them here and see how we'll go. Because we it's it's a lot of planning that goes into taking Alexander anywhere. And I can never do it by myself. I always have to have a second person. He's got a lot of cargo. So when we take them places, it's it's very like we don't leave at this time.

00;29;29;01 - 00;29;36;28

Autum

And this is what we and I mean, it's very precise, it's very calculated. So we just sit on our porch a lot of the time. We don't really go to a whole bunch of peaceful places.

00;29;36;28 - 00;29;48;19

Courtney

So you touched on this a little bit, but how did you get involved with the seed? And then why do you choose to stay active?

00;29;48;19 - 00;30;12;14

Autum

Cassie is the reason I get to in fact the seed with my joyousness. Cassie was my my son's speech therapist. We were in the hospital and she called me and she was like, Hey, I have some people that have this project in mind. They want to see, you know, they need families with a complex care, children to come into the home and ask a couple of questions and this, that and the other.

00;30;12;14 - 00;30;31;17

Autum

And and I was like, Yeah, absolutely. I'm totally down. Like, I want to get as much of Esmé out into the world as I possibly can. I need to make sure that everybody knows every single person like you know how when you are like you could say something that the whole entire world can hear at once, what would you say?

00;30;31;17 - 00;31;05;04

Autum

I would go on my estimates and I run genetic killer of children under the age of two. One, two, four. Pregnant like I would. That's what I would do. I would go on to my spiel the best way. There's just so much that goes on to the seed that I just want to be a part of. Like I always stick my fingers in everything I did Doc project and the Doc project led me to the land program and the land program took me in and I sat with these the most wonderful individual students that I've ever seen in my life that actually care, that really want to get to the to the root of helping

00;31;05;04 - 00;31;35;20

Autum

their patients. And I absolutely fell in love with it. Absolutely. Godmother to my first year I worked on and I'm still actually working on a proposal for legislation to turn birth to three to 4 to 5 because in areas in which birth to five have been implemented, the heightened education that these children experience and the better that they are that they do in school and that they learn is astronomical compared to the states that have birth to three or that don't have birth to three at all.

00;31;36;00 - 00;31;55;15

Autum

So that's kind of what I'm working on. That was a project that I work on through WebMD last year, and it's a project that I'm continuing to work on as a parent mentor through one. So I'm no longer doing the LEND program stuff. I am. I sit down on meetings and meeting clinics and stuff of that nature when I can, when I'm available.

00;31;55;15 - 00;32;18;26

Autum

And I love it. I love every piece of it because these students really care about that. They're future patients. And I want to be as as involved in that as I possibly can, because I feel like if if just one student if just one person takes my story and goes, okay, this has changed the way I'm going to interact with my patients, then I succeeded.

00;32;19;04 - 00;32;44;21

Autum

I did something great. So it's, it's Cassie that got me into, you know, the doc and then the, see, that line got me into the CBD and as I got into the seed, I kind of octopus kind of called out and put my fingers in everything that I could, whether it be the family to family or the name Genetics Regional or any anything that I can get my, my little tiny fingers on.

00;32;45;03 - 00;33;16;16

Autum

I want to be a part of it. I want to spread as much knowledge as possible. I want this student to tell me something and for me to be able to convey it to this parent right here. That means that information that wouldn't necessarily get that had had I not heard this person talking about it, had I not heard that information, I absorb it and I go, I can use this to help Tracy or I could use this to help, you know, Robin or I could, you know, I mean, all of these people that I know that have children with disabilities, that have run into things that seem impossible to overcome.

00;33;17;04 - 00;33;43;25

Autum

When I find solutions I want to share that with them. And the best way to find solutions is to have as many people looking for them as possible. And so these students are those people during journal club, they come up with the most, most just the most rainbow arguments that put together the ideas of love and help wholeness to not only like people now, but their future patients.

00;33;44;03 - 00;34;03;03

Autum

And they're intersecting each other with this kind of understanding. As long as I am asked to be a part of lend, I will be a part of one. As long as they will put up with me, I will. I want to sit in every single conference and every single meeting, every single journal clip. I just want to know what they know yet.

00;34;03;04 - 00;34;05;20

Autum

I mean, to see if I could use that to help another family.

00;34;07;09 - 00;34;21;05

Courtney

I want to circle back to the piece of policy that you're writing. Is there something that anyone listening to the podcast can do to support it, like petition or something of that nature that could support you in that I'm.

00;34;21;19 - 00;34;43;02

Autum

I'm currently right now and just the information gathering part of it, like I like I've said, I worked on it last year and I'm working on it this year as well where I just want to make sure that before I take it before anybody that it is as clear and as concise as I can possibly have it so that there are no holes in it to where somebody could be like, okay, that wouldn't work.

00;34;43;08 - 00;35;05;27

Autum

And when I say it's not just the implications of what it can do for for children in West Virginia, it's, you know, the funding for it, like where that's going to be coming from and how how to use that. And so it's like it's very intricate and it's very like I have I have all of the data from the states that have, you know, birth to five.

00;35;05;27 - 00;35;27;15

Autum

I have the data from the states that don't have any kind of birth three intervention or birth to five intervention at all. And I have the data for the states that have the birth of three and and actively you look at it, you can see it. But I know that I need more than that with the legislation for the for the as the testing for us, I may as little as I had to do with that.

00;35;27;15 - 00;35;49;21

Autum

It was still very convoluted and went through so many different transitions and like billing and committees and stuff like that. And I want to make this as smooth as possible so that I can help as many people as possible. And it's not like being held up. But the second, the second I think of anything remotely that other people can do to help, I will gladly let you know.

00;35;49;21 - 00;35;54;28

Autum

I mean, I definitely want that to be something that is as announced as possible.

00;35;56;26 - 00;36;00;06

Melina

What is a piece of advice you have for parents on similar journeys?

00;36;01;00 - 00;36;26;16

Autum

Two things, two things and two things only. Okay, when something happens to you, when something terrible happens to you, when you get a diagnosis, when when you get into an accident, when something happens to you or a family member, you have two choices. You can be a victim or you can be a survivor. You can be like, this was this is me.

00;36;27;13 - 00;36;54;23

Autum

We're going to do this my way. I have survived this terrible thing. Let's go in the hierarchy of everything. I like to think that I'm a survivor of the diagnosis that I survived. What other people would not have been capable of handling and dealing with that would have sent some people howling to the nuthouse. And regardless of whether or not you think you can do it, you absolutely can do it.

00;36;55;00 - 00;37;21;06

Autum

You absolutely can do it. If you would've told me nine years ago that I would be sitting here talking about how to help other people medically. I would laugh. I would be like, now I serve drinks to the drunk people. That's what I do. I go to school. That's it. Always be the survivor of that trauma. Always be the survivor of I did everything I possibly could to help my child.

00;37;21;13 - 00;37;45;06

Autum

And if you can't do it, find somebody like me and I'll do it. Always keep moving forward. Don't ever stop. Don't ever be stagnant. Always keep. There's always an answer There's always an answer. There's no matter what, there's always an answer whether it's the answer you're looking for or not, that's what it is. So you're either a victim and you stop and you're like, well, like, I don't know what you do and you stop and you don't move forward and you're stagnant.

00;37;46;17 - 00;37;58;27

Autum

Or you can be like, Okay, this is what it is and this is what we have to deal with. And you go forward with that. And I always say that when your feet hit the for you in.

00;38;05;25 - 00;38;21;13

Melina

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