00;00;09;17 - 00;00;31;29

Leeann

What I had to understand was that the life I had planned for myself wasn't going to be the life that I was going to live. Kyle was going to control my life and I had to give in to that. You got to follow your gut and you don't have to accept it. How some places people, doctors want to treat your child.

00;00;32;01 - 00;00;41;15

Leeann

There are human beings. My biggest term is advocacy.

00;00;46;07 - 00;00;57;27

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, Melina Danko.

00;00;58;07 - 00;01;01;02

Melina

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

00;01;01;12 - 00;01;31;29

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;32;23 - 00;01;41;24

Courtney

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

00;01;45;14 - 00;02;12;02

Leeann

My name is LeAnn Pellegrin. I am a wife and mother, a grandmother, an author, and most of all, an advocate for those with special needs. I am a mother of five sons. The first three were born within five years. I remarried ten years later. We had Kyle, who was born with special needs, and then three years later we had Alexander.

00;02;12;11 - 00;02;32;21

Leeann

I felt like the older boys had gotten a lot of attention as they were growing up. They had me. Before I remarried, I was totally focused on the three of them. And once Kyle came into the picture, the two middle ones kind of suffered a little bit because of things that we couldn't always do. But they quickly grew up and left.

00;02;32;21 - 00;02;52;09

Leeann

But Alex was a toddler and he as he got older and started into sports or wanting to go do certain things as you're reading the book, he realizes that, well, he used to get angry as he was angry because it would be like, it's too hot out, Alex. We can't take Kyle right now. Kyle's not liking it here.

00;02;52;09 - 00;03;13;08

Leeann

He's throwing a fit. You know, we have to go home early now. You know, I can't take you there with your brother by myself. And Dad is working. I was just sitting there one day, and I realized that I had yelled at that poor child probably ten times because I was trying to work and I had yelled out the window because they were yelling and I was doing transcription.

00;03;13;08 - 00;03;39;02

Leeann

So I needed him to be a little quiet. And I sat there and I saw it and I thought, Why does he bother her? Hell, you know, why will he not leave him alone? And then I just kind of thought about things. So I wrote the book to kind of tell about Alex was eight at the time and really starting to understand he didn't he treated Kyle like a normal sibling, quote unquote.

00;03;39;13 - 00;04;13;08

Leeann

Again, that's in the book. But it took him until way later in life to understand that it kind of had to give him a break. Couldn't always treat him like a normal child. But during the book, he is really kind of angry and pondering about why he always misses out on this and misses out on that. And he gets some thinking time and and realizes, you know, all the things that he gets to do even more or less makes a comparative list in his mind and all the things that Kyle does or we have to do because of Kyle and, you know, different things.

00;04;13;08 - 00;04;36;24

Leeann

And then all the things that he does without Kyle. And by the end of the book, he's realizing that, well, he gets to do a lot of stuff to Afghanistan. Just Kyle, that special. Kyle special in a different way than him. In true brother fashion, the minute he doesn't have to be in the thinking chair again, he jumps in the water and Shanghai's, you know, knowing that he's he's going to get in trouble.

00;04;36;24 - 00;05;04;10

Leeann

But he didn't seem to mind. So that I was basically telling Alex, you know, I see you, I get you. I understand what you're going through. And he didn't appreciate it then. But as he's grown into a young adult, he does now. I think the name of my book is Hey, I'm Alex. It's actually written. I think parents would benefit from it.

00;05;04;10 - 00;05;29;29

Leeann

Also teachers, but it actually is written from Alex's point of view. So I think that children, siblings especially, or people that have special needs, kids close in their age, or whether they be siblings, cousins, you know, in your classroom or things like that, it's it's kind of a lesson. But yes, it's illustrated for children as it's told by him.

00;05;29;29 - 00;06;02;27

Leeann

It's understandable. My husband, John, I met him about 31 years ago and I had three boys, Justin Unfortunately, we lost him in February. He was 38 years old. Ryan is the next and he just turned 37. He's an attorney in Morgantown. Matthew is next. He's 34 and he lives in Maryland. And then ten years later, there's Caylee Anthony and he's our special.

00;06;03;04 - 00;06;23;21

Leeann

And then three years later, we have Alexander and he's about to turn 21. When Kyle was born, he was six and a half weeks early. He weighed £4, seven ounces. He did not need oxygen, but we had a little bit of jaundice. I was used to that. Some of the other boys did. There had been ten years between he and my last child.

00;06;24;29 - 00;06;52;22

Leeann

We took him home after day four and honestly, things were normal. Normal meaning? Couldn't really pick out any differences. But once, nine months and so on and so forth hit. He wasn't crawling, things like that. He also was some very, very small no matter what we did. And when it came time for baby food staff, he was super sensitive with texture.

00;06;52;25 - 00;07;17;05

Leeann

I kept telling my husband, I think we are. I think there's something might be wrong. And he's like, all there isn't, you know, there can't possibly be anything wrong. Look, get you have three healthy boys so speed it up to like nine months. His pediatrician found a heart murmur, so they were kind of assuming that his failure to thrive being small was because of the hole in his heart.

00;07;17;05 - 00;07;35;03

Leeann

His body was working so fast that it was burning calories. Nothing else at that point because it was it was just nine months. But by the time they did the surgery, it was a day after he was a year old. And within a couple of months, I noticed that things were not progressing at all as far as milestones.

00;07;35;17 - 00;08;02;01

Leeann

So we were referred to Genetics, WVU, we went in and the geneticist at that time. One thing she had thought of one of the syndromes was Kabuki syndrome, but there was no genetic testing for it. So that was just in my husband's mind. It didn't exist in mine. I kind of look it up, did research. The one thing he did have is KLINEFELTER syndrome.

00;08;02;27 - 00;08;25;28

Leeann

KLINEFELTER syndrome is an extra X chromosome. So they have 47 chromosomes, but it's X, X, Y, and we've had to give him some testosterone shots. Other than that, we didn't really notice a big difference in some men grow up and don't realize that they have this until they go to start a family childhood and get so lucky there.

00;08;26;18 - 00;08;51;24

Leeann

He he also has intellectual disabilities. And we started noticing that, of course he wasn't maturing and the things that he liked to do, you know, or playing with the next stage of baby, baby stuff, toddler stuff, he was stuck where he was. So basically we got the diagnosis and just went from there, unfortunately, went straight to the Internet.

00;08;51;24 - 00;08;55;14

Leeann

And I do not recommend that anybody do that.

00;08;56;12 - 00;09;07;02

Melina

So with the genetic testing, how did that go for your family and and getting the diagnosis?

00;09;08;04 - 00;09;36;02

Leeann

The very first thing that I can remember at this time, Alex wasn't born. The boys were still ten, 13, 15, somewhere around there. Our first thought in our first questions were, is it fatal? That was just the very first question we asked. Know what can come of this? Will not knowing about the intellectual disabilities. You know, we went through the different things that can body features and things like that that can happen.

00;09;36;16 - 00;10;01;01

Leeann

How will we treat this? The things that we worked really hard with genetics on this and we got a good run. We were with birth to three. As far as his delays, we just we said on top of it he actually was not diagnosed. He also has Kabuki syndrome, but was not diagnosed well into his late teens because a genetic test had just become available at that time.

00;10;01;01 - 00;10;22;28

Leeann

It was kind of grasping a whole new diagnosis like this is for sure. Now, you know, what are we going to do? Well, he's a happiest for whole I mean, he has a wonderful life. You know, people say, I'm so sorry and it's it's all right for y you know, he's wonderful. He really is. And he's happy most of the time.

00;10;22;28 - 00;10;25;11

Leeann

So we just kind of went with that.

00;10;25;25 - 00;10;44;23

Courtney

And so you were you are mentioning how your husband was a little bit in denial when you were like seeing these red flags or you were noticing like differences from your other boys once you got that diagnosis. What did like processing look like and what did like mourning the loss of this idea of normalcy that you had?

00;10;45;22 - 00;11;12;24

Leeann

First of all, we had planned on Kyle being our only child together because we had three. I think that was part of it. And he it took him a long time to really understand. It was always it could be like this well, but it also says it could be like this, you know, and always looking at the good things that that could happen, which I mean, you should do, but you have to be prepared.

00;11;12;24 - 00;11;36;09

Leeann

You don't know what's going to happen as far as the boys. They really they just doted on him. The older boys, they always doted on him. Yeah. Even today, you know. So sitting down and talking to them, they were just very compassionate and empathetic. And, you know, this is my brother and I shouldn't even say that Ryan used to use him.

00;11;36;09 - 00;11;54;19

Leeann

You know, all girls love Kyle. I mean, you know, he was little. He'd be taking hold of me. Come on over. Meet my little brother. You know, quite a lot of friends and. And girlfriends got attached to him. And finally I said, you have to stop guys like you can't introduce him. He gets too attached. Yeah, they were good.

00;11;54;19 - 00;12;24;26

Leeann

The boys were good. It's taken Johnny a long time. I can remember a lot of conversations where we would be in the car talking about something or whatever, and he'd say, Well, when Kyle drives, Kyle's going to drive. You just don't say that. He's not. And every time I would look at him and say he will not drive a car, and the older he got the morning and then he started when Alex was getting close to driving age, he's like, Oh my gosh, how are we going to do this?

00;12;24;26 - 00;12;47;20

Leeann

What are we going to do? He's going to be so upset, actually, at that point, that same year, one of Kyle's good friends was actually lost in a car accident, was killed in a car accident. The whole community mourned and he really understood that. So his response was that his brother was crazy because people who drove cars could get killed.

00;12;47;28 - 00;13;11;20

Leeann

So he was fine, you see. But he never has questioned it. We do live outside of city limits now and golf carts, other things around here are so 25th birthday where we're going to get him a golf cart and of course be with him all the time. But that'll be his his driving machine. He can do.

00;13;12;24 - 00;13;15;10

Courtney

That. Sounds like it would be fun for any 20.

00;13;15;10 - 00;13;21;15

Leeann

Five year old. Right? Right. I'll be out there cruisin with them.

00;13;21;15 - 00;13;40;06

Melina

LeAnn, you mentioned that you and your husband plan to only have one child, but yet you had Alex. So how did you come to making that decision and were you worried about having another child? Since Kyle does have a genetic condition that could possibly happen again?

00;13;40;06 - 00;14;10;13

Leeann

Right. I can tell you this, there were no plans to have Alex and Matthew at 13 on probably mid-February said, I will never leave you two alone on New Year's Eve again. And immediately, I was terrified. I was Kyle was really hard at that time. I mean, he was nonverbal. He yelled for everything, you know, he could not be in the car without screaming and crying, even to go around the corner.

00;14;10;13 - 00;14;29;10

Leeann

And I thought and I worked full time and John were full time and we had the other three boys. We had just learned how to manage Kyle and I thought if, if this one has special need, I don't even know what we're going to do. So yeah, we were terrified. And the doctors, the geneticist didn't make it any easier.

00;14;29;10 - 00;14;51;28

Leeann

They wanted to do some invasive testing. And with Kyle coming early and all of that, I just I just wasn't interested in it. I guess they offer you the choice of whether or not to continue, if they would find something. And I was just completely against that. You know, I whatever God gives us, God gives us. So that's kind of how our attitude has been.

00;14;52;07 - 00;15;14;01

Leeann

So I told them no testing with Alex and he came out just like the other ones did and did everything actually way ahead of time. He was a big help because he kind of passed Kyle up and made him walk, made him, you know what I mean? Kind of made him do these things as they kind of grew together.

00;15;14;20 - 00;15;33;09

Courtney

What kind of conversations did you have with your older boys, like when you found out about the diagnosis? And then even as Kyle grew and those boys saw him face challenges and maybe discrimination, especially like in school or, you know, anything like that. Like what kind of conversations did you have to have with your children about Kyle?

00;15;33;27 - 00;15;58;03

Leeann

The most important thing was that they respect all people with special needs, and you have to understand your brother's not always perfectly behaved. I will deal with that. The biggest thing we did and we had teenagers at the time, like I said, who doted on him, but he was not their responsibility. And we assured them that he would not be.

00;15;58;09 - 00;16;24;09

Leeann

As far as you're still going to be a kid and still able to do your things. And, you know, you're not babysitters. You're not you're not you wait that your life's not going to change, which it did a little for the older guys. And then, of course, more so with Alex. But they, they grew into it, you know, they loved him so much that they understood he's I'll tell you guys, they understood when they were concerned.

00;16;24;22 - 00;16;49;18

Leeann

A whether or not there was any fatality or anything like that. For a long time, Matthew especially had that fear. Then after that, as they got a little bit older, we start talking about what happens when we're gone and specific things that we do not want to happen. We that's a very important you have to realize and I've just learned this.

00;16;49;18 - 00;17;12;29

Leeann

I lost my 38 year old son. He has two children. You know, no, buddy, you just don't know. So you really have to you know, you have to watch your kids as they grow. You have to decide which one you can put it on, which ones you couldn't, which ones are going to follow your your lead, which ones can be responsible with his trust or whatever you have for them?

00;17;13;08 - 00;17;36;06

Leeann

There's a lot in there, so you can't make a snap decision on that and you just have to reassure them that he will always be taken care of financially. You will not have that burden. But really they're fighting over him. So, you know, it's in my household, or at least he's not ever seen as a burden ever by anybody.

00;17;37;18 - 00;17;44;12

Courtney

Can you tell us what taking care of him looked like as a child? Like what? What were some of the health care needs that he had?

00;17;44;12 - 00;18;06;07

Leeann

Of course, cardiology followed him for a while. They repaired he had an SSD, atrial subtle defect, a hole in his atrium. They repaired that at WVU. The next day he was rolling over. Was Staples in his chest. I mean, he was so strong for a little guy. Once we did that, did the genetic testing, we had a lot of allergies.

00;18;06;07 - 00;18;42;09

Leeann

We had RSV like five once he got to be used pretty easy. Endocrinology has followed him ever since his KLINEFELTER diagnosis, we're still at the same doctor. WVU has been wonderful. He had kidney stones at 11. He had a very large one, and they did not have a pediatric nephrologist. They referred me to one of the best there are, and he actually had the tools imported and did, you know, went in and broke up the stone several times and then went in and retrieved it.

00;18;42;09 - 00;19;06;05

Leeann

And I mean, didn't send us to children's didn't you know, just made it as easy as possible. But Alex was just born and Kyle was three. I was in a car accident and both my legs were broken. My knees actually. So that was a trying time. But we made it through it. The boys helped to run the house and my brother came and stayed to deal with me and then John really took care.

00;19;06;05 - 00;19;30;20

Leeann

He had to juggled. We had him in daycare, we had to put him in daycare and and did that. So we faced a lot of challenges and he had so many sets of tubes in his ears, had to have his tonsils and adenoids out, like I said, the RSV. Now we've had a scare. It's a it's a skin infection on his scalp and it forms like white pustules.

00;19;30;21 - 00;19;58;28

Leeann

And we have been since before COVID following this, I had taken him over to another hospital for infectious disease, and we tried antibiotics. And then he had a reaction to an I.V. antibiotic. He ended up on maintenance antibiotics, like for the last three years. And I moved him again to dermatology at WVU. You know, you have to think about this with the with a child like this to keep them on antibiotics for three years, Kyle has to take all liquid medicines.

00;19;59;07 - 00;20;20;28

Leeann

There is no pill swallowing with him. That makes it hard. Also because the doctor I mean, the doctor at the other hospital, infectious disease, actually threw his hands up and said, what do you want me to do? The only thing the fix is it. He has a reaction, too. And that's where when I say advocate, that's when the advocacy comes in.

00;20;21;14 - 00;20;54;22

Leeann

That's when I say, excuse me, we don't that's just not even acceptable. And I did some research and I moved him to another facility, another type of doctor, to kind of push my way in the door. And his scalp is clear right now. So, you know, you you got to follow your gut. You just have to and you don't have to accept how some places people, doctors, whatever want to treat him or them your child.

00;20;54;22 - 00;21;16;01

Leeann

I don't care if your child is immobile, nonverbal, blind and whatever else. They're a human being. And that's the one thing that you have to remember. My biggest term is advocacy. Don't accept it. Don't accept less for that because it's not fair.

00;21;17;01 - 00;21;32;06

Melina

Kellyanne, you mentioned earlier that when Kyle was a child, he was nonverbal. Can you tell us how he because now you said that he talks quite a bit. So can you tell us how that transpired over time?

00;21;32;06 - 00;21;53;16

Leeann

Okay. Sure can. Birth to three. We started him with the pets cards. Once he went into the school system for you can do special education preschool. As long as they have an IEP, they can start at three, which first the three covers. So until then, birth at three provides therapy in your home and a lot of other things.

00;21;53;29 - 00;22;20;01

Leeann

We put him in to the preschool. They started him on a device that they were pictures and he would push the picture. They also started him on sign language, which we had been doing and ironically Kyle's favorite, favorite show since he was a year old was Sesame Street. So he actually learned a lot of stuff. And and Kyle, that was the only thing that would soothe him.

00;22;20;01 - 00;22;41;03

Leeann

So we can't have a child all upset, screaming, crying, refusing to eat. So, you know, with him, we let him watch it. Then we noticed about two years old, still nonverbal. I mean, he would say stuff, but you couldn't understand it and you would just have to follow his tone. But he has a love for VHS movies to this day and DVDs.

00;22;41;03 - 00;22;57;16

Leeann

But the VHS tapes were popular back then, and he would take, gosh, even as a baby, he had a lot of but he would say, say a stack of ten and he would rip them out of what he now calls their moms the cases they were in. You take them all out and just scatter them all over the living room.

00;22;57;16 - 00;23;21;22

Leeann

And I'm like, go ahead. You know, you're you're busy. But he would match them up perfectly. He would put them back in. There were no pictures on the tapes, no pictures at all. And then he started putting together that. At that time, all Barney tapes were white, all blue school tapes for orange, and he would sort them. They kind of wanted to throw them into the spectrum.

00;23;21;22 - 00;23;38;09

Leeann

Again, I had to advocate and push and pull and say, no, no, no, no, we're not going there. You know, just because you want to line up the colors. Once he did that, they got they got him. He had the machine for quite a while. And then he started talking more and more. Of course, he always had speech therapy.

00;23;38;09 - 00;24;04;29

Leeann

You could understand, even if you couldn't understand him, he would spell it. If he could get to anything where he could spell on, he would spell it on a machine or a computer. He'll spell it verbally. Now, even if I don't get something, you know, he'll start spelling it. Once he got into middle school, they gave him an iPad and just about that time he had figured out the Internet on his own.

00;24;05;12 - 00;24;29;21

Leeann

So he worked on that quite a bit. He was always in special education by the time he was in high school after like his freshman year, everybody understood him. I mean, it wasn't like he had friends, he had peers. Everybody was wonderful. He has great friends still to this day. From there, he didn't it wasn't like he had to walk through the hallways and do everything on the iPad.

00;24;29;21 - 00;24;55;26

Leeann

I mean, he had conversations. Karl doesn't have up to date conversations. Karl's interested in movies and his stuff, you know what I mean? And what's going on. And he does little soap operas and with his friends, I know everything about all about them and what they're doing, what they had for dinner and all that. So, yeah, he, he just progressed, I mean, and birth to three, the school system just kind of helped us along there with what he needed.

00;24;55;26 - 00;24;58;22

Leeann

So he, he sometimes talks too much. Now.

00;25;00;04 - 00;25;03;04

Courtney

What were some ways you had to advocate for him in school?

00;25;03;23 - 00;25;30;11

Leeann

Oh, my goodness. I can tell you at the very beginning and again, my boys are a lot older, my older boys. So they went to Fairmont Senior High. We were polar bears. We lived two streets away as Kyle was getting towards middle school. I have a good friend in special education and in these departments and a relative. And you know, we would have conversations like where are you going to send him for high school?

00;25;30;21 - 00;25;57;29

Leeann

And I said, I'm going to send to Fairmont Senior. They didn't have a special education program at Fairmont Senior. Well, I'll tell you this. My boys graduated from Fairmont Senior. Kyle is in seventh grade. You have two years to get a special education department at Fairmont Senior because he's going to graduate where my other four boys graduated from.

00;25;58;12 - 00;26;19;15

Leeann

This is a family tradition, and I did it nicely. You know, I didn't say, you know, I do this or I did. I did it nicely and I worked with them. And you know what? They did it. They did it a year before he got there. And then, you know, we had some problems with one of the aides not wanting to do certain hygiene things that you just have to do because Kyle's he's gained a little weight.

00;26;19;15 - 00;26;40;07

Leeann

Is he gotten older? He doesn't have a really good balance. It never did. It's very hard for him to do certain things. So he does need help, or at least watch to make sure that he completes the task. And I fought that for months and every day he would come home and I would notice the same thing. I would go right back in March in there.

00;26;40;21 - 00;27;09;03

Leeann

And this is not acceptable. What do you need? Well, we don't know. We don't have these at school. Well, I'll tell you what. I'll bring these to you. I will make sure you have all the supplies that you need. But this has to be done. And I stayed on it and she did what she needed to do. And then we got fortunate and his aide from middle school actually transferred over because she had was so close to that set of kids that they were all over the high school.

00;27;09;03 - 00;27;35;09

Leeann

Now that she just wanted to be with them, the one thing you want to do is you want to make sure that people follow your rules when it comes to your child. Young adult, adult Kyle's going to be with us all of our lives, God willing. Everybody in this family pushes for him and I can tell you, you teach them advocacy and they'll do self-advocacy.

00;27;36;01 - 00;27;53;19

Leeann

Kyle was very young when we went to just to give you an example, we went to a festival and we were sitting at a table, Kyle, my sister Alex and I, and we were eating ice cream and there were four elderly ladies sitting at the other table. And because of the way he was talking, you could understand them.

00;27;53;19 - 00;28;14;03

Leeann

You couldn't, you know, things, and they could tell they were staring at him and he happened to be facing them. And so was I. And all of a sudden he handed me his ice cream and he got down and he walked over there and he said, What you looking at? And I think, you know, at that point in time, I was proud of him.

00;28;14;03 - 00;28;36;20

Leeann

He knew. And that's what I mean. Don't you don't know what these guys are thinking and you don't think they notice you staring at them or talking about them or something like that? And I'll tell you the truth, I have confronted many people in many stores very quietly and letting them know you should be ashamed of yourself or your child should know better.

00;28;36;26 - 00;28;45;29

Leeann

And I hope to teach that to other parents. It's it's the most important gift you can give them is to advocate for them.

00;28;45;29 - 00;29;00;04

Courtney

We interviewed someone once who said it was so important for her as an adult now with a disability, to have watched her mom advocate for her so that she learned how to do it herself.

00;29;00;18 - 00;29;01;13

Leeann

Absolutely.

00;29;01;13 - 00;29;10;04

Courtney

And that's what that just reminded me of, because now she knows how to address it. When people are being inappropriate in her presence because of the way that her mom did it for her is absolutely.

00;29;10;04 - 00;29;24;06

Leeann

And she can be stern but not rude. You know, you don't want to go over and going over and giving them a hug and saying, please don't do that. I mean, people some people need to hear from them.

00;29;24;06 - 00;29;26;07

Courtney

Yeah, not everything needs to be sugarcoated.

00;29;26;24 - 00;29;33;17

Leeann

No. Oh, gosh, no, no. It can't be done in today's world.

00;29;33;17 - 00;29;53;28

Melina

And she had also mentioned to that when it came to her own children and advocating she she had learned that if she didn't advocate on their behalf, that that was also setting a standard for them, that it was okay for somebody else to treat them that way. 1% I thought that that was a really powerful statement and viewpoint.

00;29;54;21 - 00;30;17;21

Leeann

It very much is. It very much is. And and I think more my boys because they were older they that happened naturally ten years is a big and 15 years and 13 years is that that's a big hop so that came naturally. But Alexander there being younger at home, we were terrified. We were just like, oh my gosh, you know what's going to happen?

00;30;17;21 - 00;30;39;04

Leeann

Well, and and one when he was out away like daycare or something, he was his biggest advocate. So even though he pretended like he didn't know what we were saying or doing or, you know, didn't think Kyle needed one, he really was he he really went especially once they got in the same schools and things like that. He was really proud of his brother.

00;30;39;17 - 00;30;59;18

Leeann

He did a they brought him over to Fairmont Senior when he was in eighth grade and Kyle was in 11th and he specifically sought out his classroom and went in and hugged him. And that was just, you know, in front of his friends here you are going into high school. Didn't matter. Did not matter. What do you do that at home?

00;30;59;18 - 00;31;23;04

Leeann

Absolutely not. So, yeah, they do. They do. They do. And that's good because you know what? You know, when you're gone, they've got it. They've got their backs. It's that's the most if you don't have severe health problems, your biggest worry is what's going to happen when you're gone. And that's really brought into clarity lately in our family.

00;31;23;04 - 00;31;25;09

Leeann

So that's one thing you worry about.

00;31;25;29 - 00;31;28;09

Melina

LeAnn, could you tell us about Kyle? Now.

00;31;29;01 - 00;31;49;12

Leeann

Kyle is very involved in stepping stones at Morgantown. He does life skills there on Wednesdays, which they truly go out of their way to, you know, things you need to know. How do you behave in this situation? How do you do this? How how do you do that? And then they have fun things to do in the evening if you want to come in for a class.

00;31;49;12 - 00;32;14;23

Leeann

So we'll also go for they have day camp Monday. He'll be a day camp and Friday he'll be at day camp. They get a lot of exercise. It's really great for him. His peers. There are more his age. He has very close friends. Kyle is a very personable young man. He loves people. He stays busy playing baseball. On Tuesdays, we do just about anything and everything.

00;32;14;25 - 00;32;40;07

Leeann

We're very involved still with Marion County Special Olympics, I was the executive director there, but one of my good friends is doing it now and we are involved with them. So he gets soccer in, he gets bocce and he gets bowling in pink. That's about it with them. Plenty busy. My life is his life. I'm the chauffeur as far as for me to deal with them.

00;32;40;25 - 00;33;01;27

Leeann

He is very loving towards me. He will slip up. He will raise his voice. Lately I've had to tell him that we can't do that. I've had a hard time with anybody doing that here lately. Of course, you lose a child, it's. It's hard. So he promised that he's going to try not to do that. He's a little bit harder on his dad.

00;33;01;27 - 00;33;21;20

Leeann

That is me. I don't know why, but he is he takes great offense. I think it's because John is a typical Italian dad. You're going to do it because I said you're going to do it. And why are you still arguing with me and things like that where Kyle just he's going to get the last word and you just it's a it's a an approach method.

00;33;22;04 - 00;33;55;17

Leeann

You can't go at them hard because they'll they'll either act out or you won't listen. And Carl's like that. You have to watch your tone. But I make him watch his tone with me also. You know, it goes both ways. So life with him now is three meals a day, almost at the exact time you will be reminded we still do self-care as far as showering him, helping him with toileting, we brush his teeth because he was born with an anomaly of teeth and permanent teeth missing.

00;33;55;17 - 00;34;19;15

Leeann

And very so we very religiously have got everything sealed and everything to keep the teeth that he has. We cut his nails dressing still. He can do it. A lot of times he needs help. Turning it around doesn't have a clear label in it, and he doesn't like tags to cut all the tags out. Shoes, socks. I help with shoes.

00;34;19;15 - 00;34;42;05

Leeann

As long as he comes and checks with me, are they the right feet? He'll put them on. So basically we're still taking he's he's my full time job. He's very independent at home now. He'll he loves his movies. He has conversations. He has his own iPhone. He faced tons people. He probably got 20 people lined up at night that he talks to every night.

00;34;42;20 - 00;35;09;26

Leeann

He goes to bed when he wants. He gets up when he wants. He doesn't break the rules. He doesn't get into the cabinets. He doesn't eat unless can I have a snack? He's pretty, you know, as far as we just help him along in life, that's that's what I'm doing. I'm helping him along and making sure he has a social life and making sure he's clean and healthy and that he's a good part of society and taking contribute something.

00;35;09;26 - 00;35;15;14

Leeann

And he does he contributes a lot of happiness to the world. He does.

00;35;15;14 - 00;35;19;18

Courtney

What are some of Kyle's skills and strengths and special interests?

00;35;20;09 - 00;35;46;03

Leeann

Milk Special interest are the movies. When I say movies, guys, I'm talking preschool movies. He loves Barney. He loves Blue's Clues. He loves all of those that were popular Elmo when he was little. A lot of people will try and buy him and some of his brothers will try and sneak in SpongeBob or someone that or we have to get him something more mature.

00;35;46;23 - 00;36;13;22

Leeann

And it's not he won't watch, but he also values his movie as people like he plays with them like this because these three are in a series. There are brothers. He knows every birthday of every movie that is on his top 100, I guess. I mean, it's amazing. He'll group them by category things like if they have the same closing previews, that's what he calls them anyway.

00;36;13;22 - 00;36;39;18

Leeann

So that the Internet, he can run, run rampant. He will not get on anything that he's not supposed to do. He's very good about that. His cell phones. Funny, because Lord forbid I see a message that comes over and they're all completely innocent. But he he hides, he puts it, flips it down. And if he notices that I glance that way because I'm trying to reach something, he'll he'll walk over there and flip it over.

00;36;39;23 - 00;36;59;00

Leeann

So we monitor everything. He does. But he is very independent. He he loves to cook. But, you know, that's that's hands on with me except for a few things, you know. COOK You just that you scoop out of a tub. He can do that. We stick around and just watch him in the oven and things like that. Would I leave him home alone?

00;36;59;07 - 00;37;07;00

Leeann

No. You know, he's very independent. No, he doesn't have any fear of danger. He doesn't think ahead to consequences.

00;37;07;26 - 00;37;11;26

Courtney

How has Kyle changed your family dynamic and perspective of.

00;37;12;28 - 00;37;59;27

Leeann

I would say Kyle has has made our family 100% better. He makes us all the best person that we can be. He is so happy and so just loving and hugging. You know, none of his brothers have any issue with kissing him in public, kissing. He wants everyone to kiss his head. It's taught us a lot of it's humbled us, the other boys, especially because they were heading into the teen years and they got to see the difference in their brother and maybe thought back to some classmate that they had maybe talked about or made fun of or, you know, done something.

00;37;59;27 - 00;38;04;16

Leeann

I think their perspective on that community would be different had they not had.

00;38;04;16 - 00;38;18;07

Courtney

Kyle So along those lines, what would you say are like challenges? Because, you know, you're a large family with a child with special need and then at the same time, like what about is like a benefit.

00;38;19;07 - 00;38;40;10

Leeann

Challenges are still what they were when he since he's been born. We have to integrate anything we do into stuff that he can tolerate or somebody stays home. A lot of times he doesn't want to do something. And we'll have to like say we're going to say mom and dad are going to the grocery store and you're going to go with us.

00;38;40;19 - 00;39;02;00

Leeann

And we had to run another errand. We by the time we get to the grocery store, he doesn't want to go. You can't drag him in there. It just wouldn't be pretty for anybody. And he's too big to pick up. So, you know, I'll stay in the car with them. A lot of things I missed because I couldn't take Kyle to a 12 hour wrestling day for Alex, things like that.

00;39;02;16 - 00;39;31;08

Leeann

Now, the pros, I mean, we have such a loving community. I would not trade the people in our special needs community and the contacts that I've made and the friends that I've made and and family we've inherited, that is the biggest blessing of all. Find a mom, these special needs moms. When we first headed in at 11 into you know, I wanted to get him into something.

00;39;31;08 - 00;39;59;25

Leeann

I wanted to make sure he couldn't do the things at school after hours. So I wanted to get him into something. But a lot of the moms for 20, 30 years older than I was at the time, and they're still doing it at 70. But we are a strong force and we help each other out. And not only with these kids, with with any of their kids, when I lost my son, I mean, that community pulled together and they were there before family, honestly.

00;39;59;25 - 00;40;28;28

Leeann

So it's that's got to be one of the number one. The second one is you learn to appreciate their milestones. And my biggest thing I've always said is, love your kids for who they are, not who you want them to be. So, you know, you're not going to compare your children and you're not going to compare him to another one of your children and little things you celebrate with him.

00;40;29;23 - 00;40;51;18

Leeann

The whole family celebrates. He really brings us together. I mean, I post pictures with him with each one of his brothers, and they have the biggest smiles on their faces whenever they're with him. He calls them. They face time him all the time. They know what's going on in my life every second of every day, even if they haven't talked to me for three days.

00;40;51;21 - 00;41;14;19

Leeann

So he stays in close contact. That was one of the hardest things of losing. Gus just was very, very he he really wanted our family close. He was the oldest. And he made sure he contacted Kyle and I every day. So we had a hard time after my uncle would say to me, you know, nobody me like he did, you know and know I'm the same way.

00;41;14;19 - 00;41;27;00

Leeann

And so the boys pull together for him. They're really making an effort to call him and to keep keep in contact with them. So it I do believe we have a different dynamic without him.

00;41;28;13 - 00;41;35;25

Melina

But planning conversations have you had to have with your children about Kyle as you age?

00;41;35;25 - 00;41;55;12

Leeann

One of the things that we had to do before we even could speak to the children, we have to make sure and you have to try and make sure. I know not all people can do this, but hopefully you can not burden your family financially. Try to do anything you can to set a little bit of money aside.

00;41;55;12 - 00;42;17;25

Leeann

You know, of course they'll get their disability once they're 18, not before unless they have a very low income family. But once they're 18, they draw it on their own. But I had to set specific rules like somebody is going to have him, we're going to have this conversation. Honestly, I would be very disappointed if I don't want him placed anywhere.

00;42;17;25 - 00;42;39;14

Leeann

Do you guys agree with that? Oh, my gosh, we would never place him. You're going to have to keep him in his activities. You guys can't take him in and just, you know, put him at your house and then just go on. There's going to have to be somebody wanting them to realize the vast just how many things they're going to have to do to maintain his lifestyle.

00;42;40;07 - 00;42;55;29

Leeann

And as they get to be adults and they get to be older, they really understand what you're saying. They see what I do and they have to make that decision within themselves. I may get one that comes to me and says, Mom, I'm going to be honest, I can't do this. You know, just don't even consider me. I can't do it.

00;42;55;29 - 00;43;14;13

Leeann

And would I be mad or upset? No, I would be happy because I want Kyle to be in the best place. You do have to prepare about. It's really hard, I think, for people with just one child and having one special needs child. That would be my biggest fear.

00;43;14;13 - 00;43;19;07

Courtney

And and what kind of conversations regarding that have you had with Kyle himself?

00;43;20;22 - 00;43;46;02

Leeann

It's kind of funny because a lot of times he won't do he knows he's going to go with one of his brothers, depending on who's doing the most for him at this time. It's the one he wants to go to. If he's not talked to Matt in two days but talked to Ryan 14 times today, he's going to Ryan's house, but I try and get him to do more things for himself because I'll say, your brother's not going to do this for you.

00;43;47;00 - 00;44;04;05

Leeann

Oh, yes, he will. Oh, no, he won't. I'm telling you, you need to do this. I said, you know, first of all, it depends on which brother. But no, then they're their wife will do it. And I'm like, Kyle, no, we're going to learn. But I have to keep in mind too, I want him to do these things.

00;44;04;05 - 00;44;28;01

Leeann

We just moved a year and a half ago. We've had some stuff. We had John's mom sick and stuff, but we have a bathroom that's right off his room and and really we need to install a few things, I think, for him to be able to be more independent in there. So a lot of that's on me because it's easier, just like you with your kids, it's easier just to do it.

00;44;28;18 - 00;44;45;14

Leeann

It's easier just to do it and be done with it. But I think we're going to get some physical aids for him, some things to make him feel a little bit more secure. We've got some bars in the shower, but they're the kind that suction on, you know, you want to get get a walk in, shower made and stuff like that in that bathroom.

00;44;45;14 - 00;45;05;14

Leeann

We do them in our shower because it's a walk in now. We try and prepare him and tell him, you know, one day we're not going to be here. Kyle, unfortunately, has seen a lot of people pass. He just lost his grandmother two weeks before brother. But before that, I mean, he had a lot of his friends were older and they've passed.

00;45;05;28 - 00;45;36;03

Leeann

One reason I wanted to get him in a social community more towards his peers that was really hard on him. A lot of them just have certain diseases or things where things happen. A lot of them have gotten an accident. So he understands he won't feel the depth of the emotion until it happens. But my kids know that how important I am to him and they and they really are taking it seriously, like they're going to have to measure up.

00;45;36;03 - 00;46;01;14

Leeann

They're going he's going to have a really hard time when something happens to us. So someone's going to have to step up big time no matter what they're diagnosed with. Write a list, go home, not that day incident or just whatever you have in your mind there. That's fine over the next few days or whatever. Write a list of questions or come to you.

00;46;02;04 - 00;46;28;27

Leeann

Try to find people to talk to rather than do research on your own. The Internet's a scary place when you're dealing with this, unless you want to find a support group. And Facebook course makes that really easy right now. And nowadays, back then I had to just go through the web and there's a filters syndrome group. And, you know, I talked to a lot of parents.

00;46;28;27 - 00;46;52;26

Leeann

They had chat, chat rooms and stuff. I think that's your biggest benefit right there. Try and keep your child with the same doctor. I know a lot of people have to move and things like that. Kyle has it's been very beneficial to me for him to have the same pediatrician all of his life, the same specialists, the ones that took him as pediatrics, now still continue to see him.

00;46;53;02 - 00;47;15;16

Leeann

Nobody's booted him out. There are pediatric dentists. Please take care of your child's teeth, no matter how hard you think it is. And they're not going to tolerate it. Kyle Gags and gags and gags and has he even vomited? But you need to really get them to the places where they need to be and and my biggest thing is don't accept anything less.

00;47;16;01 - 00;47;39;03

Leeann

Don't accept anything less. If, if, if the doctor treat your other child and you think that that doctor should treat this or dentists say said this child, and they're hesitant, you could say, okay, let's try, let's try. And if you decide you can't I decide that that's fine and I understand. Then I will go for a specialist, but give them a chance.

00;47;39;12 - 00;48;14;26

Leeann

Don't let anybody turn them away until you've you've tried because some people are afraid. Kyle has given us great gratitude, probably, that we wouldn't have had. We've appreciated his milestones more than we possibly would have. Key is a great example for other kids. He's very helpful. He loves to be helpful. He loves to make friends. He loves to connect.

00;48;14;26 - 00;48;42;29

Leeann

I mean, he's a good he's a joy. I honestly do think maybe God gave me Forever Child for a reason. I am very nurturing. I have a really hard time. I get so many animals because I love to nurture something and he makes me happy. My oldest son, Justin, he and his wife decided to have another child. They had an 11 year old girl and of course, she wanted a sibling also.

00;48;42;29 - 00;49;09;15

Leeann

And that was really huge to them. So Livvy was born June 22nd, 2021 in Colorado. Casey still in her early thirties and didn't see any reason to go in and do genetic testing or anything. Livy was fine through all the ultrasounds and everything. There were no signs of anything. She was born early. When she came out, my son sent me her first picture.

00;49;09;16 - 00;49;25;29

Leeann

I looked down and I said, Down's syndrome and I didn't say anything to them. I thought, How do you feel about this? And I thought it just brought me joy to see her. The next day I talked to my son and I said, How she doing? He said, Mom, they're going to test her for Down's syndrome. And I said, How do you feel about that?

00;49;26;14 - 00;49;45;08

Leeann

And he goes, What do you mean? And I said, How do you feel about his? I don't feel anything about it. He said, If she hasn't, she has it. You know, it's fine. He said, you know, Kyle told me that it's no big deal. I said, Buddy, I said, We just won the jackpot. I said that if you have to deal with anything, this is this is going to be fun.

00;49;45;08 - 00;50;08;11

Leeann

We're going to it's going to be fun with her because of Kyle and because of the fact that her sister had come out here every summer since she was two and was raised with Uncle Kyle. But with Live, everybody was excited. Everybody was we were so happy. Her mothers got her out there and birth to three. I was able to guide her and look for the things that she needed to have.

00;50;08;16 - 00;50;27;01

Leeann

I got her started on the pets cards and things like that, and really that's a true joy to me. I would love to be able to help other parents just know how to get started. Unfortunately, we lost Joss. That was her father. So the girls are moving back here. They bought a house here and we are going to just tear it up.

00;50;27;01 - 00;50;48;03

Leeann

And then Down Syndrome world, there's so much that that we have yet to explore and it's a good small community. Casey will get to be involved with the parents, my daughter in law, and she'll get her her group of parents will get her involved. And we're just going to have a blast with it. You know, it's nothing nothing that we're worried about.

00;50;49;02 - 00;51;08;19

Leeann

If anybody would like a copy of my book, get a hold of me. I'm on Facebook. We can Pellegrin and we can get it autographed for you, though. Anybody would like a reading in a classroom. I'd be glad to come and do that. So we're just we're just going to keep having fun and see what we can do for these guys.

00;51;08;19 - 00;51;24;06

Melina

This podcast is sponsored by the West Virginia Department of Health and Human Resources Office of Maternal Child and Family Health. Children with Special Health Care Needs Program, and the West Virginia Family two Family Health Information Center and produced by the West Virginia University's Center for Excellence in Disabilities.