00;00;00;00 - 00;00;34;07

Gennifer Friend

Having a special needs medically assisted child sometimes can scare people away and I hate that there's a stereotype against it. Yes, it's scary, but there are people to.

00;00;34;09 - 00;01;02;14

Melina Danko

It. We are your hosts, Courtney Ring staff and Milena Danko with the center for Excellence in Disabilities and the West Virginia family. The family Health information Center. With each episode, we bring you real conversations with parents, caregivers, professionals, and advocates people who understand your journey and share your stories. Whether you're here for encouragement, information, or just to feel less alone, this is your space.

00;01;02;16 - 00;01;28;19

Courtney Ringstaff

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

Gennifer Friend

My name is Jennifer and I am an almost 30 year old with five children. Four of them were adopted, and we do have one biological son who's a year old. My oldest three are eight and we have a six year old.And then of course we have the baby. The little fellow that we're going to discuss today is my six year old. We have had him since he was born. He has what is called HIV, which is the lack of oxygen and blood flow to the brain that can happen during your birth or after the birth. He was born with a heartbeat but was not breathing.

00;01;55;28 - 00;02;26;07

Gennifer Friend

And after he was born and they worked on him for a little while, they had to fight him over to the nearest children's hospital where he was at that time, and Roanoke, Virginia, which is roughly about six hours from my house. We actually got acquainted with this little fella because of the job I had at the time. I actually worked with one of the family members to Whalen, and she she got Ahold of my main boss and was like, hey, I really need to talk to Jen.

00;02;26;09 - 00;02;34;15

Gennifer Friend

So that's initially what started. It was because I worked with a lady. She knew my journey.

00;02;34;17 - 00;02;55;23

Gennifer Friend

My husband and I had struggled with infertility for several years. I had actually woken up at 230 in the morning one day and I was like, listen, what are your thoughts about fostering and adoption? And he was like, I've never thought about it. He was like, I cannot thank this man enough because he was so genuine through the whole entire thing.

00;02;55;23 - 00;03;14;18

Gennifer Friend

He let me lead the way because he's like, I just don't know how you're feeling. And he said, you lead the way and I'll just pick up the pieces. And that that's exactly what this man had done. Actually, in the middle of our process to be certified, we actually did get pregnant. Unfortunately, we ended up losing that baby.

00;03;14;21 - 00;03;34;15

Gennifer Friend

And something that kind of brings it a little bit full circle was the year to the day of that happening. We brought Waveland home when he was born. They had originally told us that he would probably be in the hospital for about four months, because of the severity of his case. He actually got to take the drive down to Roanoke and meet him.

00;03;34;15 - 00;03;58;22

Gennifer Friend

And like I said, it was six hours one way. So we went down on the 28th of August and they're like, well, you have to go through all you have to meet all of his entire medical team. They all came in and started talking to me, and then there was one nurse that completely caught me off guard and walked in and picked him up and just sat him in my arms and just walked away like she didn't say anything to me.

00;03;58;22 - 00;04;26;18

Gennifer Friend

She didn't make any eye contact. And I was like, we're gonna take his baby homes. There's no way you don't care what they're going to tell me, because it doesn't matter. And then they came in and they basically told us with the statistics of his condition. Unfortunately, there I know one other family that has a little boy that has the same diagnosis, but, his case isn't quite like Wayland.

00;04;26;18 - 00;04;46;29

Gennifer Friend

And I think that's kind of what makes it such a unique diagnosis is because everyone is so different. And basically when we were at the hospital, they told us, your child has seizures and he may never walk or talk, but this is all we can provide to you right now. And they were like, well, after he passes all of his tests, he can go home.

00;04;47;02 - 00;05;07;20

Gennifer Friend

Well, they started doing tests while we were there and he's just passing them, like with no problem. When originally they told us that would be four months. And so they were like, he might honestly be able to go home in a couple of days. And I was like, oh, okay. And they said, well, we can put you in the Ronald McDonald House because this was definitely over our 50 mile radius.

00;05;07;22 - 00;05;24;20

Gennifer Friend

And I was like, oh no, I cannot stay here because I have to go home because we have absolutely nothing ready. They had told me that that the mom did not know that she was pregnant and actually had just went in to be checked out, and at that time the doctor was like, well, you're crowning to have a baby.

00;05;24;22 - 00;05;45;23

Gennifer Friend

So actually, when the family member to this lady had contacted me, her exact question was like, do you know what I could do with the baby or do you want it? And at that time, I was like, what kind of baby we talking about? Are we talking about an animal or a human? Because this was at 9:00 at night and she's like, oh, it's a human baby.

00;05;45;23 - 00;06;05;04

Gennifer Friend

And I was like, where did you find one of those? Because I was just so taken back of like, that was the conversation that we were having. And she was like, we have an unexpected baby. And right now the mom is not ready for that type of commitment. Actually, Courtney is the one that I had to call. And it was like, what do I do?

00;06;05;04 - 00;06;25;01

Gennifer Friend

Because it's just was so out of the box because we had we had known that we had completed a, a private adoption portfolio. So we just always assumed that we would have time to prepare. And it was already done for us. Like I did not anticipate just being call and be like, here, do you want this baby?

00;06;25;03 - 00;06;53;18

Gennifer Friend

And I think this is a good time to just chime in and talk a little bit about my background. I'm now your host of Adjusting to sales, but prior to being with the center for Excellence in Disabilities and prior to adjusting the sales, I actually worked in foster care and adoption. And this is what led me to meeting Jen and I was her home finder, and I helped to certify her family to be able to foster and adopt.

00;06;53;20 - 00;07;22;21

Gennifer Friend

And so the process that she's discussing is not typical for adoptive families. Typically, birth parents create adoption plans with their adoption workers and decide that an adoption is the best option for their baby. They have the opportunity to look through parent profiles of certified families that that agency has opened, and they have the opportunity sometimes to even meet in advance.

00;07;22;22 - 00;07;49;10

Gennifer Friend

And so this particular circumstance was unique in the way that it happened quickly. And it happened by Jennifer being contacted directly because she was identified at her workplace by a coworker whose relative was having a baby unexpectedly. And so she reached out to us and not the other way around. And so this whole situation happened a little bit backwards, but I think things happen for a reason sometimes.

00;07;49;10 - 00;08;20;05

Gennifer Friend

And Jennifer was in the right place at the right time, and she met the right people. And Whalen was certainly meant to be her son. I did not anticipate bringing him home within 13 days. And from start to finish, and birth mom actually was very helpful in the whole process because she kept her rights during his entire hospital stay, because there were just so many medical decisions we had to make.

00;08;20;05 - 00;08;39;00

Gennifer Friend

And if she would have, if she would have signed her rights over right then and there, the state would have been able to make the medical decisions. And at that point we were like, we don't want that to happen. And she was okay with doing that for us. And so after we wacker, we picked him up, was when she did sign over the rest of her rights to him.

00;08;39;03 - 00;08;56;07

Gennifer Friend

And so, I mean, I'm forever thankful for that because anything that was going on, she would call me be like, this is what the doctor's telling me. What are your guys's wishes? She actually let me name him a couple of days after she had had him. They had asked her if there was a name that they could give the baby.

00;08;56;07 - 00;09;26;07

Gennifer Friend

And she's like, well, let me give you a call back. Let me ask them and see what they might have picked out. So I actually got to name Whalen at birth. And he's just he's had that name since, since he was a newborn. We still do have contact with bio family. Not as much that I would think that we would have, but she was very wanting to separate herself but also be involved when she could be like she always make sure to tell him happy birthday.

00;09;26;10 - 00;09;39;00

Gennifer Friend

She will usually contact me on Mother's Day to wish me a happy Mother's Day and that type of thing. So, I mean, I usually hear from her about once or twice every year.

00;09;39;02 - 00;10;06;28

Gennifer Friend

One of the things that he struggles the most with his HIV is he does have seizures. And from the day he was born until February, the they had prescribed him phenobarbital at Roanoke Hospital because that was the only thing that would work for him at that time. And when we got him up to where we are from, we actually transferred all of his stuff to WVU for the Children's Hospital because it was much closer to us.

00;10;07;00 - 00;10;29;06

Gennifer Friend

And the neurologist that we were paired with was not comfortable with Athena Barbara at all. So we started doing a weaning process in February of 2020 to get him off of that, to see if one if he really, truly needed it and if he did put him on a different medication that was more safe for his body and his organs.

00;10;29;09 - 00;10;56;22

Gennifer Friend

So in February, he was completely weaned off of it. So we went from February to November of 2020 with no medication at all. He did really well until the 4th of November, and his seizures came back, and they came back with a vengeance. The seizure had lasted an hour and 15 minutes. I still to this day, the nine on one call haunts me because it was like he was fine.

00;10;56;22 - 00;11;20;20

Gennifer Friend

And so about I mean, he was not mean. He obviously wasn't fine, but he was still in our response until about until they were about a mile out from us. And then he quit responding and was foaming from his mouth. I remember when they had picked us up in the ambulance, they said, he's going to be LifeFlight, but you can't come with us because at that time is when Covid really started to intensify in our area.

00;11;20;23 - 00;11;52;00

Gennifer Friend

And we are we are roughly 45 minutes to an hour away from our hospital. He did respond to the reversal seizure medication that you had given him, but they couldn't promise me that he would make it and things could be different. By the time we arrived at the hospital. And so my husband and I drove down there, and when we had walked into the E.R. at the time, because now, Ruby has two sections at this time, it was still just one big hospital.

00;11;52;02 - 00;12;14;28

Gennifer Friend

They didn't have the children's section off at this time. They had direct us to us, to his room. But we walk in and he's not there. And so I immediately started panicking because the last time I had saw him, he was unresponsive. So I instantly started panicking and I had to came out of the room and I had found a nurse and I was like, do you have any idea where my baby is?

00;12;15;00 - 00;12;39;23

Gennifer Friend

And she's like, no, honey, I don't, but I can find out. And about that time, they had to roll him around the corner because I had started going testing on him immediately. As soon as he got there, they had their like EKG, the baggies, everything to see if there was something underlining that might have sparked a seizure, to come back and come back so quickly because we didn't even get any type of an alarming like there wasn't days leading up to it that he was different.

00;12;39;26 - 00;13;03;08

Gennifer Friend

He was literally pushing one of his toys around our house, walking, and it just went into one. So there was like no prepping or anything that even remotely let us know, like, hey, this is what's about to happen. So at this point, the doctor that was on call said that he is definitely a candidate of needing seizure medication, probably for the rest of his life.

00;13;03;10 - 00;13;26;06

Gennifer Friend

And at that time, they put him on Keppra because Keppra doesn't attack his organs. It was the more safe option. And at that time, they did not tell us that there was a thing called cap rage. And I guess a lot of people actually struggle with this is if they take keppra, they end up with with what they call cap rage because it switches their mood.

00;13;26;06 - 00;13;46;23

Gennifer Friend

And he became very mean and angry. So we had to have a conversation of like, is there anything that we can do separately that might help with this mood that he has? And at that time, they actually recommended us to give him vitamin B and I and I and honestly did work. I was kind of shocked at that.

00;13;46;24 - 00;14;09;08

Gennifer Friend

And it was just a bad I mean, I can reverse some of his mood swings that he was having, and he was on that just keppra for a few years. Of course, they would have to increase his dose every time he would gain weight or anything would fluctuate their. And then about in the last year, almost two years, he has outgrown just the keppra.

00;14;09;11 - 00;14;35;04

Gennifer Friend

So he actually has to take two medications now for his seizures because they're very complex and they are not the type of seizure that I would think of when I was a kid of like body movements, like he's completely is he staring? He was his consciousness. And like I said, we do live at 45 minutes to an hour away from the children's hospital, and we no longer have an ambulance service in our area.

00;14;35;07 - 00;14;57;22

Gennifer Friend

And so we had to sit down with his team to create a plan of something happen. So he has two forms of medication that he takes daily, plus we have a seizure rescue that we would give to him if he is having a seizure for longer than five minutes. And like I said, like with his seizures, they don't just last like a few minutes here and there when he has had a seizure.

00;14;57;25 - 00;15;17;00

Gennifer Friend

We're looking anywhere from 30 minutes plus. And so we immediately load up in our car and start getting on our way to Morgantown. Just because I know it's it's not going to be an easy process. It's going to just be a few minutes and we're fine. So we already get in route to a hospital to having checked out.

00;15;17;04 - 00;15;21;17

Gennifer Friend

Even if his reversal does work.

00;15;21;20 - 00;15;47;26

Gennifer Friend

When we brought Whalen home, one of the big things that they had told us was early intervention will be the key to trying to get him to have a normal, somewhat of a normal life. And of course, with us working with the foster care system, we, already had avenues through birth to three because we are my oldest son had birth to three as well, so we got him enrolled through birth to three.

00;15;47;26 - 00;16;13;14

Gennifer Friend

So we used O.T. and then we later went out of speech because he does not communicate very well. He like he'll point and stuff like that, but just sit down and have a conversation. He kind of looks at. He is just kind of more standoffish. Like if he really need something, he'll Wheeler like, walk us to it. Or I swear the older ones talk for him.

00;16;13;14 - 00;16;29;28

Gennifer Friend

Like they just know what he wants and they're like, hey, mom, he's wanting this as a this is what he's needing. And I don't know if it's just true or if he just agrees to it, because when we give it to him, he's fine or they just had their own communication, I don't know. So that is one thing that we do struggle with is a language barrier.

00;16;29;28 - 00;16;55;07

Gennifer Friend

He has been deemed you're an incompetent and but we still have him. So I, I will I'll take with whatever they give us because we still have a little boy that is growing and is flourishing every day. And that was not what we were given at the beginning. Like we were told, like, you'll be lucky he ever locks and he runs and he he elopes.

00;16;55;07 - 00;17;19;26

Gennifer Friend

That is one. Another thing that we do struggle with is because he does a lope. He has no fear whatsoever. So we have ADT, we have cameras, we have extra locks, we have the sensors and all the things. Because that is something that he does very frequently. And we have different mechanisms that we use outside of the home, like when we're at a store and that type of thing.

00;17;19;28 - 00;17;44;01

Gennifer Friend

He doesn't really do well with crowds, overstimulation. He gets really upset, he cries, and it just looks like panic. And so we do try to keep him away from big crowds. So my oldest wrestles and plays a bunch of different sports. And that's just one thing that Whalen doesn't get to really enjoy. He doesn't really get to go with us because it's just too much for him.

00;17;44;04 - 00;18;10;09

Gennifer Friend

Tell us about how he integrated with the other children or how they integrated with him, because I know they didn't all come into your family at like the traditional way. Right. All right. So how did that go? So the four oldest ones are the are the ones that we have adopted. My oldest son is he actually is a he's not the first child that we ever took, but he was the first child that has been able to stay with us.

00;18;10;09 - 00;18;32;23

Gennifer Friend

So RJ has literally went through this entire life with us being the bigger brother to Whalen. So he is his protector. Everything that Whalen needs or wants, if I can't get it to it immediately or he takes care of it, RJ usually goes to every appointment with me when it comes to Whalen, because he one wants to know what's going on.

00;18;33;00 - 00;18;59;24

Gennifer Friend

He wants to know if they have any other ideas that we can kind of do to help him. RJ always talks about how he wants to become a doctor because of Whalen, because he wants to help children like Whalen, because he's already done it. According to him, they so so RJ has them with Whalen. So if we brought him home now, my youngest daughter, she came into his life almost, almost two and a half years into Whalen life.

00;18;59;27 - 00;19;25;19

Gennifer Friend

She integrated very well. She's really calm. She's more relaxed. She usually is very understanding. Now, one of the things I said as he dealt with rage, so he had a tendency of like smacking and hitting for a while until we could get everything leveled out. So he. That was one thing you could tell. It kind of just broke her heart, because I remember her asking if he liked her one day and I was like, kind of.

00;19;25;20 - 00;19;43;21

Gennifer Friend

He really doesn't understand, like what he's doing. It just he's just doing it because that's how what he feels like, which is not acceptable. So you either tell him no or you remove yourself from the situation. So, I mean, she did have the fear of like, him not liking her. There was just something that was wrong. And so we did have to have that, that talk with her.

00;19;43;27 - 00;20;10;01

Gennifer Friend

But they overall she watches them a lot too. Like she if they're outside playing, I can hear being like, well you can't go over there. It's not safe. And so they've done really well. Our oldest daughter, she also has several diagnosis and I mean, when you when you're getting children from the foster care system, you don't a lot of the times typically they're not coming from good backgrounds or they wouldn't be in the system to begin with.

00;20;10;01 - 00;20;35;22

Gennifer Friend

And her backstory is very, very sad and difficult. And so she really just did not know what to do with a child that was like Whalen. She didn't understand why he would just randomly scream, why he would throw things at her, why he had any type of reaction to her the way that he did. And she, she was just as combative.

00;20;35;25 - 00;20;56;21

Gennifer Friend

And so we we did struggle for a while with our oldest daughter and Whalen to try to get them to kind of walk into a same room without having a disagreement or an argument, because she just didn't understand. I will say, within like the last year or so, I've seen her calm come out of her shell to work with Whalen more.

00;20;56;23 - 00;21;19;19

Gennifer Friend

She doesn't do it as much as the other two, because I just don't think she knows what to say or what to do because he really doesn't communicate back. She didn't grow up with that while the other two did. And then and then like, I mean, even with our family, everyone has with it's Whalen that's there. They've just they've switched their mood of like, what do I need to do for him?

00;21;19;21 - 00;21;44;07

Gennifer Friend

It's never been like, Whalen is an inconvenience. They just switch whatever is going on with their day to, well, this is just how it's going to have to go today because Maitland's here. And that's where anywhere that we've went with our families and stuff like that. And then like I said, after we therefore oldest ones were adopted and we actually do now have a biological son, and he's a little over a year old now.

00;21;44;07 - 00;22;07;23

Gennifer Friend

And that was something that I kind of, I did worry about for a while was how Whalen is going to do with a baby that doesn't leave, because, I mean, we still fostered for a while after we had gotten Whalen and but they never stayed. They were here for a couple weeks, couple months, just whenever they either went back home with their biological parents or they would go on to something else.

00;22;07;25 - 00;22;25;23

Gennifer Friend

So no one ever stayed here permanently. So I just I just didn't know how I was going to take it. I didn't know if he was going to be mad or feel like he wasn't any more like as important because he like I said, he doesn't communicate. And we were in the hospital for five days with the baby.

00;22;25;23 - 00;22;43;17

Gennifer Friend

And when we came home, that had been the first time I had ever been away from Whalen. His entire life was when I went to have the baby, and so I struggled with not having him. I struggle with not knowing what was going on all the time, so I was just so excited to see Whalen. And when he seen the baby, he want anything to do with me.

00;22;43;19 - 00;23;00;25

Gennifer Friend

But no one else was allowed to hold a baby. He every time someone else would hold a baby, he'd go over and try to take him. And so I was like, okay, well, maybe this isn't going to go so bad, but I was like, again, this baby doesn't leave. So we'll see within the next few weeks, months how this is going to go.

00;23;00;27 - 00;23;27;20

Gennifer Friend

Well, to this day, Whalen, like us, Whalen will not have a conversation with just anybody. But Whalen will sit inside this big play yard that we have for the baby and sit there and have a conversation with him all day. Like he uses words. He sits there and giggles and they play together. And I always and I my family and I both have said they just have a they have their own communication that they just understand to each other.

00;23;27;23 - 00;23;46;25

Gennifer Friend

And and we always say that like the baby was a blessing to Whalen because that is something that really has popped him out of his shell. And the baby walks now. And so like, Whalen will chase him around the house like, no baby, no baby. That's not okay. And so within like the last 16 months, we have seen Whalen blossom into a new person.

00;23;46;25 - 00;24;17;27

Gennifer Friend

Like, I think he knows that he's a big brother and he has a different type of bond with him. And it's just been beautiful to watch. I love that, and I wonder if he somehow sensed too, that that that baby needed him, where maybe with the other siblings they could help him. And so then he was able to to sit and nurture a little bit and that, you know, resonated with him a little.

00;24;18;00 - 00;24;38;21

Gennifer Friend

Yeah. I mean, it's it's honestly very beautiful to watch because, I mean, we all were worried about like how this was going to go because he's just never and this was a newborn newborn. It wasn't a baby that was able to set up by themselves yet or anything like that, what he was used to. And so where I, I just really, honestly didn't know how this was going to go and that he loves his baby.

00;24;38;21 - 00;24;54;04

Gennifer Friend

And even in the car they sit right beside of each other and if the baby's crying, he'll be like, oh no, oh no. And then he'll be looking for like his car for just trying to get him anything that would keep him calm. And I just would never have thought that this is where we would be with Whalen.

00;24;54;04 - 00;25;16;02

Gennifer Friend

I never knew I never thought that we would see that type of reaction out of him. This coming year will be actually his first year in school, which I run a private school. I had homeschooled my older ones for a year, and then I had decided that I wanted to make it available for other parents that couldn't homeschool their children, to have a place of secondary choice for school to go.

00;25;16;04 - 00;25;30;06

Gennifer Friend

And so we will actually be starting his first year of school. And I'm like, I don't know how this is going to go. I don't know if he's got to stay in his classroom or if he's going to be like, nope, got to be up here with my brother. So it's gonna be interesting to see how this is going to turn out.

00;25;30;06 - 00;25;54;11

Gennifer Friend

He definitely does not. He will not learn the same as another child would because we've tried like different books and stuff, like old trays, that type of thing. But just sit there and like listen to a lecture. He will not do that. But then I've always was the parent, like, I'll never have iPads, I'll never have tablets. But I've had to make that transition for Whalen because that is something that he does try to do.

00;25;54;11 - 00;26;16;04

Gennifer Friend

And he will sit there for hours and answer questions about letters and stuff like that. So that might be the way that Whalen has to learn for right now is something that is actually online and not that book, because he he just doesn't care. He will just look at you like you're not getting anything out of me. Can you talk about the support system?

00;26;16;04 - 00;26;38;03

Gennifer Friend

I mean, obviously you have a very strong support system because you have fostered and adopted a lot of kids, and you've needed parental and other extended family supports. But how like, has Whalen specifically, you know, how does that change your support system dynamic with Whalen? Everyone is very, very protective of Whalen, of my side and my husband's side.

00;26;38;06 - 00;26;59;23

Gennifer Friend

The only thing that we do struggle with is not everyone's comfortable to keep him overnight because of the clothing, the medication and just the fear of the seizures because, like I said, they're very significant. They're not just a couple minutes and he comes out of it. It's usually prolonged. So that was something that we I don't I don't think I don't want to say that was a barrier.

00;26;59;23 - 00;27;20;15

Gennifer Friend

It was just that no one at that point was comfortable enough to keep him. And I respect that that like, I respect the fact that you're coming to me. I mean, like, we'll keep him for this amount of time, but overnight, we're just not ready for that. So I would say that's the only thing that we, kind of at the beginning had a little bit of a back and forth concern with.

00;27;20;18 - 00;27;48;08

Gennifer Friend

But everyone, I mean, they just they make him feel special. My, husband's parents have a total of 14 grandchildren, and not one of them are singled out like they. And they are. Usually every one of the grand children are usually there every single day. And she pays just so much attention to all of them. And like, I've seen her get down to his level and be like, I'm not really understanding what you're saying to me, buddy.

00;27;48;09 - 00;28;08;28

Gennifer Friend

Like, can you show me? So like, everyone just knows, like he just communicates in a different way. So they try to transition to that for him. And I'm like my mom and my grandma all go out of the way and find things that could encourage him to do more. And like my mom, she had, she had made she's like, make sure you cover the fact that he loves crafts.

00;28;09;01 - 00;28;28;11

Gennifer Friend

And there was one day he actually sat in that classroom at school and made macaroni necklaces with everybody else. And I did not know that he could hold a string and, like, thread it through the macaroni. And he did it on his own. And so, I mean, we kind of they all try to make sure that there's something that he can do to.

00;28;28;13 - 00;28;56;18

Gennifer Friend

And I, I'm very thankful for that because I it could have went either way. Having a special needs medically assisted child sometimes can scare people away. And I hate that there's a stereotype against it that it. Yes, it's scary, but there are people to and I think sometimes we've kind of failed to realize that. And just like the way that people outside of our family addresses things kind of bother me.

00;28;56;20 - 00;29;19;15

Gennifer Friend

And one of the things that we dealt with when he was a baby is I we wouldn't I wouldn't go out anywhere to eat. We wouldn't go out as a family because I was because he wasn't so easily soothed, because he just he lacked that. And so there was times he would just yell and scream and I'd get upset and people would just because people would be staring at me.

00;29;19;15 - 00;29;33;09

Gennifer Friend

And I remember a time that I got, I was going to get up out of the booth that we were sitting in and just go to the car and just keep him an eye on the car while they finish their meal. And my grandma was like, you will not. That baby deserves to be here just like everybody else.

00;29;33;09 - 00;29;52;23

Gennifer Friend

You will not do that. And from that day forward, I just I let it go. And so I just from that point forward never really allowed it to bother me. And with RJ, the oldest one, oldest boy playing all the sports, even like the sports families like, oh, hey, there's Waylon, Melissa, keep an extra eye on him today.

00;29;52;26 - 00;30;10;22

Gennifer Friend

And so, I mean, they just all kind of just learned about Waylon and his diagnosis and like kind of what to look forward to. So like anytime that we're at events like everyone kind of just keeps an eye on him because they just know. And which is that's really been a blessing because at first I didn't know how that was going to go either.

00;30;10;24 - 00;30;28;06

Gennifer Friend

I didn't know if I would have friends that were supportive or anything like that. I knew my family would adjust because my aunt's daughter had struggled with some disabilities as a kid, and she still to this day does so. I knew my family would transition very well to that. I just didn't know how the outside world would be.

00;30;28;08 - 00;30;50;15

Gennifer Friend

When we think of disability, we think of the physical. And when you look at Waylon, Waylon looks fine and what you would call, I guess, normal. And so when then when he acts out or he is struggling with something, what kind of get some of that backlash from people that don't know him like why is he not potty trained or why does he do that?

00;30;50;19 - 00;31;10;29

Gennifer Friend

And, I mean, I'm a very open book. Most people will say that because I, we talk about our infertility journey. We've talked about our fostering journey, all of it. Because if I can help one person, I've done my job because I do think there is that. Well, when we think about disability, we're thinking about physical features, and that's not always the case.

00;31;11;02 - 00;31;37;29

Gennifer Friend

Oh, and another thing that I've we've tried to we've been communicating with his, neurologist about on his medical plan is something that we've noticed with him late within the last couple years is weather changes seem to really affect him, and we don't know if it might be like the barometric pressure in there when that's storming. But I know by his behavior that our storm's about to come because he starts getting to the point where you can't see with him.

00;31;38;02 - 00;32;05;14

Gennifer Friend

He kind of just runs rampant. And so we kind of all just learn as a family, like we're going to go home, we're turning all the lights off, we're going to watch movies, whatever we can do to keep him at a baseline. And as long as we're at home, I haven't seen him struggle as much. But if we're out and about like shopping or just doing some type of activity that we're trying to get through the day and it starts storming like he will, he will sit in this car and scream the entire time.

00;32;05;14 - 00;32;29;20

Gennifer Friend

So that's something we we can't obviously say yes, that this is what's occurring, but it is something that we have noticed that he does struggle with weather changes and storms. Loud noises have never affected him, which I thought was really different. He's my husband, has dirt bikes, four wheelers, all the things, and he used power tools all the time for building and doing different things like that.

00;32;29;23 - 00;32;48;16

Gennifer Friend

And that is something that never really seemed to affect him, which I thought was kind of different. I figured that type of thing would either one scare him or be too loud for him. And he's never he has never struggled with that. He loves fireworks. We have to watch with him watching the like, the glow and the light from the fireworks because of his epilepsy.

00;32;48;20 - 00;33;06;29

Gennifer Friend

But he he loves stuff like that. Actually, when he was like, why did they had to do like a strobe testing for his seizures. And he was obsessed with the lights. And I'm like, you can't, but if you can't. And I know, like with toys, a lot of the toys for babies, they light up and we would still get him toys like that.

00;33;07;01 - 00;33;34;15

Gennifer Friend

We just never allowed him to play with them in the dark. We made sure that it was daylight. So like the light reflection wasn't there to emphasize anything because I was afraid that lights would trigger and they never have. And we never really have found an avenue of what would what really affects him or what causes them. We don't know if he maybe just has weight gain, his body structure changing and he just like grows that dosage.

00;33;34;15 - 00;33;54;21

Gennifer Friend

And at that point that's what's triggering. We just have never figured out a cause. And then like he had a he actually had a seizure right before I had the baby. We're at a wrestling practice and he was just eating and had went and went to his blank stare. And we got into the hospital and we had to stay overnight and do some testing with him.

00;33;54;24 - 00;34;25;07

Gennifer Friend

And he does have, he does have a significant amount of seizure activity at night, which was always something that I didn't worry about. Is that I wouldn't be able to help him because he was asleep. Something that we've we've tried to look into, but we haven't been able to get it figured out, is maybe like doing like one of the cubby beds or having a service animal, because if I could be alerted that something's about to go down, I have that extra time to get to a hospital and I just I've never found the right avenue for that.

00;34;25;07 - 00;34;56;29

Gennifer Friend

So hopefully one day we can make that happen for him. Because if I could give myself a peace of mind, that would be great because I just I think that's one thing that a mother with a child that has disabilities, if they if they could, obviously we can't prevent it. But if we could be more prepared to say, this is what's happening, we've got to get there, or the fact that I can let my guard down just a little bit, and I feel like I'm always on some type A level because I'm constantly worried about, like, what's going to happen.

00;34;57;01 - 00;35;17;21

Gennifer Friend

And he he has no fear of water. And that is something that scares me because of his eloping, because that is what he lives for. Every time. And if it's the end, I mean, we do have dogs and stuff here at the house that try to, like, corral him out of different things that they know that he's not supposed to be in.

00;35;17;24 - 00;35;41;18

Gennifer Friend

But I think if he had something specifically just for him that would be beneficial. And I just we just have never found like the right avenue for it. But like I said, we've done all the security that we could potentially think of. And he wherever he drops at night to sleep, that's where we usually let him lay, because if we try to move him, he gets a little mad and starts throwing things at stuff like that.

00;35;41;18 - 00;36;05;14

Gennifer Friend

So where he kind of falls on ice where he sleeps. But and usually that is in the living room. So at least to me, if I can just walk out of my room and see that he's fine, I'd be better with that. Instead of having to, like, crawl back through the house wherever he's comfortable, I leave him, but also kind of gives me a peace of mind for as his mom, that I can just literally look at my out of my bedroom and see that he's fine.

00;36;05;16 - 00;36;21;06

Gennifer Friend

We have a huge beanbag chair that he sits in all the time, and that seems to be his comfort place. And so that's one thing we're trying to look for, for his schooling is some sensory things that kind of like hug him, to get him to stay in place, to learn as he goes with his peers and stuff.

00;36;21;06 - 00;36;43;26

Gennifer Friend

So hopefully that will work. Just your average setting doesn't really help. Always help for him that you would typically think of. And like I said, every his case is even different than the other child. And I know in our area because that he, the other child in our areas play sports and Whalen cannot because he doesn't understand.

00;36;43;29 - 00;37;08;21

Courtney Ringstaff

Could I ask a question, about you in this manual? So obviously raising children with special needs and raising children who have histories of trauma and abuse and neglect, like, those are like the two things that often drive couples apart. But you and the Daniel have been together for a really long time, and you continue to, you know, keep your homes and hearts open.

00;37;08;21 - 00;37;34;17

Gennifer Friend

And so what is what is the secret or what is the advice that you could give to two couples who are looking to grow their family by adoption, or who might be considering adopting a child with a disability and how can we protect you as a couple? So communication 100% is key. Any time, any time that we've ever had to make a decision, the communication has been the outcome.

00;37;34;17 - 00;37;57;19

Gennifer Friend

Like if we talk about it, we strategize anything that has been what has been most benefit to beneficial to us. I will say so. Nathan is very, very quiet. I am not so like definitely the opposite. Opposites have attracted in this scenario. I have seen him become more of an advocate through this journey than I would have ever anticipated.

00;37;57;20 - 00;38;30;11

Gennifer Friend

Like he is not afraid to speak up when it comes to our kids. He, he goes to every appointment that he can go with us. Any time that Whalen has ever been hospitalized, he has been right there. Actually, I should have brought this up earlier. When? When Whalen was airlifted to, to Ruby in November of 2020, when Covid was in force in full swing, they had us in the E.R. while they had told us that, well, he's getting a room and asked my husband if he wanted to move his vehicle out to the front of the hospital so it would be easy, accessible when we leave.

00;38;30;14 - 00;39;03;01

Gennifer Friend

So Nathan left to go move a vehicle around while Whalen and I got transferred to another room. When Nathan tried to come back into the hospital, they refused to let us in his room until Whelan's Covid test came back. So there was just the Whalen and I in the room, and then they wouldn't let Nathan back in. I tried to convince this man to go home or even go to his mother's house, and he would not be slept in the hospital parking lot until Whalen test came back negative.

00;39;03;07 - 00;39;27;11

Gennifer Friend

He was absolutely heartbroken. Nothing I said changed anything. I was like, at least go home and be comfortable or go to your mom's and be comfortable. He would not. And then he came back around like 3 or 4 in the morning to be like, hey, it's negative. And as soon as I messaged him, he came right up. He has been a godsend when it came to any of our journeys, and we talk about everything we discuss, like what our next avenues are.

00;39;27;15 - 00;39;44;00

Gennifer Friend

I mean, he usually does typically let me leave lead the way because I'm comfortable with talking and he's not. I think that was our biggest thing. It was just being able to talk about it. We we talk about the good, bad and the ugly. We have a really good communication. We've also known each other since we were young.

00;39;44;02 - 00;40;08;09

Gennifer Friend

We went to church together when we were like five and six and stuff like that. So we've always just been around each other our whole lives. And then his parents and stuff like that were very accepting of me, so I think that helped as well. He overall had a pretty calm upbringing. So the foster care system really, he was like, people really do stuff like this.

00;40;08;09 - 00;40;30;19

Gennifer Friend

This is what happens to children in our area. So I think that was kind of an eye opening thing for him. And it turned into, I want to save every kid and what I say by every kid. We had 21 children in our house and four years. So, we definitely try to keep busy because he was like, I just want I either want to be a voice or I want to change a child's life.

00;40;30;21 - 00;40;54;20

Gennifer Friend

And so I'm thankful for the husband I have, because I don't know if I would have had that same outcome, if it was anybody else. Express how you feel, even if it's not the greatest. Like if it's if it's a con, still talk about it because they might have an idea of what would help you process that. If there's more than one person communicating about the same topic, you can bounce ideas off of each other.

00;40;54;22 - 00;41;13;00

Courtney Ringstaff

I'll never forget interviewing Nathan. You were at work and I was interviewing him for his home study, and I said, you know, if you could make one change in your relationship with Jen, what would it be? And he said, I think I would just I think I would just go back and find her sooner. And I said, you've known each other since you were five years old.

00;41;13;00 - 00;41;34;20

Gennifer Friend

How much could you have gotten? I he I mean, we did. So I mean, like I said, we did have, we did grow up in a church together. I would only ever see him really on the weekends because I live with my, my mother and I was visit my grandma and my dad on the weekends. And so that's the only time we ever really would see each other.

00;41;34;20 - 00;41;57;02

Gennifer Friend

And until we got into high school and we're just two separate, two separated people when we got to high school. So we really never communicated. Then. And after I had graduated, I had moved to a new location to go to college. He actually ended up getting struck by lightning and it fried his truck. And he came to the dealership that I was working at to buy a truck.

00;41;57;02 - 00;42;18;17

Gennifer Friend

And that's actually how we rekindled it is because he got struck by lightning. He tells everybody the story. And we kind of were just joking one day and it kind of led us to where we're at. And so I think that's where he gets from is like, if he could change anything that we probably would have been together earlier on in our life, other than just like the separation of just growing up as a person.

00;42;18;19 - 00;42;24;08

Gennifer Friend

And I agree, I was like, how much more time did you need?

00;42;24;11 - 00;42;54;04

Courtney Ringstaff

Well, thank you for sharing your story. I do wonder if you have any advice for parents who are considering adopting or fostering children with disabilities. I mean, I definitely listen to their story. Even like even just regular referrals. We we broke them apart. Each referral that we ever received was scary in a sense. And if we really one of went off of the referral we received about our oldest daughter, we wouldn't have her because, I mean, hers was hers was very intimidating.

00;42;54;06 - 00;43;19;01

Gennifer Friend

And we had sat we talked about it, we had prayed about it. We thought about every avenue that we could use and how she's here. She's been a doctor for a few years now. We she does, she does has flourished. And I think don't don't be afraid to really break that referral apart. Listen to what your medical, your medical family has to say.

00;43;19;03 - 00;43;43;22

Gennifer Friend

Actually, the reason, because I first was very scared of accepting a child with, a disability. And actually, one of the families on the panel was what really helped us say, like, we could open our house a little bit more because I was once that parent that was like, no, I can't do it because once I'm there, I'm not an emotional person until it comes to children.

00;43;43;22 - 00;44;05;15

Gennifer Friend

And then I'm like, then I'm a whole mess. But listening to their story is kind of what opened us up to the possibility that maybe we could do this. So, I mean, don't go into it just saying, like, no, we just absolutely cannot. I definitely break it down. Think about what you can do and what you couldn't do as a parent.

00;44;05;18 - 00;44;33;13

Gennifer Friend

See if you have that right support system. And I think that was really what made us comfortable all saying, yeah, we can do this is because we did have a very good support system. We work really good. We do work really well as a couple. Thank you. You do you share your story so beautifully and I feel like you have just a way of making things sound relatable.

00;44;33;16 - 00;44;57;09

Melina Danko

Like, I think that people will be able to really resonate with a lot of the things that you've shared, but also not feel so scared or intimidated by them. So for that, I want to thank you for sharing because there's a lot going on in your house, and I know even just to sit with us for a little bit of time is it takes a, a village to be able to sit and give us this attention.

00;44;57;09 - 00;45;15;06

Gennifer Friend

So thank you. Right. That's why I had to call in for reinforcements because I was like, I know they're going to be wild the whole time I the call. But I mean, it just I thanks me being strong enough to be an advocate for my children have definitely benefited the fact that I can sit and talk about these things.

00;45;15;08 - 00;45;35;16

Gennifer Friend

And like I said, I've always been very open about everything. I mean, we've had to make changes. And his mental health, his medical path, because we've had pediatricians that just refuse to listen to us. And they wanted to view it as there was an issue about outside of his diagnosis and were sending us all over the place for different medical treatments.

00;45;35;16 - 00;46;01;28

Gennifer Friend

And I'm like, I'm done with this. If his neurologist is not concerned, I'm not dealing with it. I'm not putting him through more uncomfortable testing unless she has a concern, because his head is smaller than the average because of his brain injury. And so, I mean, I think advocacy was has been a huge reason as to I had to be strong, I had to make these decisions, and I've had to do it for all my children in a different way.

00;46;02;00 - 00;46;26;07

Gennifer Friend

And that's what I've always said. I was like, if at any point I can help drive a family to want to foster, to adopt, I will, I will do that. I'm not saying that it's easy because it is not. It is scary. You have days that it works well when there's days that you struggle. You just have to have the right mindset and have the right people that are surrounding you.

00;46;26;09 - 00;46;46;25

Gennifer Friend

He's a totally different child that they had told me that he would be. He's had a more beautiful outcome that they had anticipated and I can't be upset with that. Like he he moves mountains. We all, we always call him wait on the warrior because that is just what he's been.

00;46;46;27 - 00;47;03;05

Melina Dank

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