00;00;09;23 - 00;00;35;00

Robin

You would think, how can a person that cannot speak a word have such an impact on people? You can't get caught up in the diagnosis and the day to day you have to look and appreciate that person for who they are. And that's why I can say I would do it all over again. I would do this exact journey all over again.

00;00;35;09 - 00;00;50;05

Robin

I've grown to love this life, and I know that you will, too. But you do have to look at it through a different lens.

00;00;55;07 - 00;01;06;29

Courtney

Welcome to Adjusting to 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;01;07;10 - 00;01;10;02

Melina

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

00;01;10;13 - 00;01;41;01

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;41;23 - 00;01;50;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;54;15 - 00;02;27;22

Robin

My name is Robin - Hatcher and I live in Flat Top West Virginia. I'm married to my husband, Chuck Hatcher. We've been married for almost 31 years now, and we have three wonderful children. Hayley, our oldest, she just turned 20. And she's going to be the one that we're going to be mostly talking about today. And then I have twins that are almost 14 years old, boy and a girl, Mattie and Slim Hayley, is a wonderful, wonderful blessing to us.

00;02;27;23 - 00;02;58;18

Robin

Just to give you a little bit of a picture of what she's like, I'll tell you a little bit about her diagnosis. She has severe spastic c.p. Down's syndrome. Cortical blindness dystonia peri ventricular aluko malaysia severe scoliosis with more than 100 degree curve and chronic lung disease. And then she has a host of secondary diagnosis. In the last couple of years, she's really declined.

00;02;58;28 - 00;03;22;29

Robin

We've seen a lot of issues with wanting to sleep all the time, along with intense breathing issues, especially in the last six months and she can't talk to us. She's never said a word. So it really we have to use all of our senses in order to figure out what's going on with her. But really, she she's a wonderful person.

00;03;22;29 - 00;03;46;27

Robin

She smiles, she laughs. She understands things. She loves to listen to music. She loves to swing on the swing outside her favorite shows. Her favorite movie is The Sound of Music with Julie Andrews. I would say if you would do a view on Attune, she has watched that movie more than any person in the world, I would think.

00;03;47;01 - 00;04;12;16

Robin

So she knows all of the songs and she just makes her vocalizations that she's very happy. And and then she loves Elmo. She loves the backyard again, really a lot of anything with music. She loves she she just enjoys any type of music. She's a person that is a joy to hang around. We call her the Earth Angel.

00;04;13;09 - 00;04;34;09

Robin

She is the only one in the house that we say, you know, she doesn't have a flow. She she's never had a scene as far as a willful sin. She doesn't hate people or in the she's not jealous. What she gives is love. If you can get her to smile, it just you feel like you've won the lottery.

00;04;35;03 - 00;04;57;05

Robin

So all of us love to hang out in her room and just to be around her and hear her laugh. He just enjoys life and she's content with where she's at. Who wouldn't want to be around a person like that? I remember telling my mother, We know what if I have a child with Down's syndrome? I've never been around anybody really.

00;04;57;05 - 00;05;28;01

Robin

That was handicapped before. I don't know. I just sort of had an inkling and I do feel like it was God preparing me. But when I went into the doctor at around 17 weeks in pregnancy, they did a test on me called an Aspie. And it really wasn't to detect for Down's syndrome, but it was a marker. They called me at work and told me that the chances of me having a child with Down's syndrome would be a one in 52 chance and that there was false positives.

00;05;28;01 - 00;05;51;06

Robin

And I just really felt like I would be the one I did. I really felt like I would be the one. It was pretty traumatic. I was around 32 weeks and all of a sudden this very active baby inside of me just completely quit moving. She quit moving, really, the night before. And I was concerned, but I just thought, wow, I had a stomach virus.

00;05;51;06 - 00;06;09;29

Robin

So I thought, well, maybe it's just because I'm sick, but the next morning I went in to work. Still no movement whatsoever. I called the O.B.. They told me a few things to do. And if that didn't work, to come in at noon around 7 p.m., they did an emergency C-section on her. And so she was eight weeks early.

00;06;10;13 - 00;06;32;14

Robin

We spent a couple of days at that local hospital. They had suspicion that she could have Down syndrome. Her tone was very low, which is common for kids with Down's syndrome. They did bloodwork, but it would take about a week. They told us so that was a pretty agonizing week waiting. But again, it's she was so little, she only weighed £3, eight ounces.

00;06;32;14 - 00;07;00;21

Robin

I didn't really see anything that would make me think that she had Down's syndrome just by her features. But yet inside, I just really felt that she would and she did. We spent about three weeks there. We were in the queue the entire time and it was pretty amazing because I remember praying that God would give me just an extraordinary amount of love for this human being, because I knew she would need it.

00;07;01;16 - 00;07;33;13

Robin

I knew that she would need people that would care about her and that would take care of her. And that motherly love kicked in immediately. In fact, when we were separated and again, I only knew her two days other than being inside of me when we were separated from the helicopter ride. As soon as I got to the hospital, I went to the McHugh and they told me it wasn't visiting hours, and I just started bawling and they finally let me in, even though it wasn't visiting hours.

00;07;33;13 - 00;07;54;15

Robin

But I had a fight. At the very moments I'm going to I want to see her. I want to make sure that she's okay. God was equipping me to advocate into flight from the very beginning, and then I had this great amount of love for her. I was longing for someone to relate with me. My parents couldn't relate.

00;07;54;17 - 00;08;20;15

Robin

I had no friends in the same boat as I was in. I just had in my mind that I would have this life like everyone else did. You bring home a healthy baby and you do all the fun things and you get to watch the milestones and they grow up, they get married, they go to college, and all those realities started kicking in immediately that those things were not going to happen for me, it wasn't going to happen for me.

00;08;20;23 - 00;08;46;20

Robin

And so I really started grieving those first couple of months. In fact, I cried every single day, but mostly cried over the fact that what would happen when I died? Who was going to take care of her? I was already grieving that and it's just the love of the mother is going to take care of you until the end.

00;08;48;14 - 00;09;07;29

Robin

I remember there was these two ladies that walked into the Nikki one day and they were all put together and they were talking to everybody. And I just thought to myself, I just don't want them to come over here because I don't feel like talking. There is no way you can relate to me. I was just in my head.

00;09;07;29 - 00;09;34;01

Robin

I was just so not wanting this. But they came over and I was kind to them and let them talk to me. And what I found out was that they could understand me. They had children very similar to what Haley was like. They would be my contact people for the next couple of years. They were parents, network specialists, which is what the CB does there.

00;09;34;02 - 00;09;59;20

Robin

So that was my first introduction to what the other side of the fence looks like. I didn't want to cry all the time. I didn't want to be in despair. And these ladies showed me that there is hope that you're not going to be sad all the time. It really helps me and I pick myself up and was able to function better after that.

00;10;00;01 - 00;10;27;00

Robin

The first couple of years of her life was the hardest because I got so many diagnosis during that time. We went from Down syndrome and then we found out she was blind and then we found out she had C, P and all of those things were very hard to deal with. She had very high muscle tone. It's like her body was so stiff and she cried out with spasms.

00;10;27;13 - 00;10;48;08

Robin

And we were just searching for people to help us. Again, we were in this world and we were trying to navigate and we we just didn't know what to do. So it was a lot to figure out. And those first couple of years. And then I wasn't used to people coming into my home. I went from no one coming to.

00;10;48;08 - 00;11;11;26

Robin

We had someone here five days a week. We had birth to three interaction, and Monday through Friday I had seven therapies for Haley. Just trying to help her to get better or to get stronger. So that was very overwhelming. I remember them writing the notes, the verses re they would have to write a note at the end of the session and just reading it and I had to sign it.

00;11;11;28 - 00;11;38;17

Robin

It just, you know, just sort of put it all in my face again, what she would never do. And it was very hard to just deal with that reality. I mean, she got a little bit older. We had her in church with us and the pastor had this little segment for the kids. And I just remember feeling so hurt because my kid couldn't walk and she couldn't go up there.

00;11;39;02 - 00;12;07;26

Robin

I definitely in those first, probably up until about three or four, I was still adjusting to the loss of everything. In the beginning, you really don't know what to do and what's needed. As time went on, we have prepared things in such a way to help her in her life. Like, for instance, her medications, they're all labeled container.

00;12;07;26 - 00;12;33;02

Robin

Like we have these little containers that we purchased at Hobby Lobby. They're all different colors and every medicine is crushed in a particular color of container. We use things like shoe organizers to put on her door to put her supplies in. We use drawers to put other things that she needs medically in. And really for us, we're very thankful.

00;12;33;11 - 00;13;07;28

Robin

We built on we have a stock room dedicated daily because living with her, it's really like an ICU setting. There's there's machines, there's lots of supplies. And if you go low on supplies, it's you can't always easily buy things at Walmart that the specialized things that she needs. It's sort of like you figure out things as you go and you do want to get as organized as you can because otherwise it just sort of drowns you.

00;13;08;08 - 00;13;34;10

Robin

The day things can drown you. And so I know if you'd like more ideas, feel free to reach out to me because I wouldn't mind sending pictures or things like that because it is it's it's hard for families to figure this out because you're so overwhelmed with all the other things. But really, the day to day things can really make you feel like you're drowning.

00;13;34;28 - 00;13;59;12

Robin

Probably the best advice I got was from a mother I got in contact with. Her child had Down's syndrome. She said, I don't wake up every day thinking my son has Down's syndrome. I just wake up and love him. I love him for who he is. I decided that I was going to do that. I was just going to love Haley for who she who she was.

00;13;59;12 - 00;14;23;20

Robin

And she was a wonderful person. I love being around her and something else that really helps me. If you have never read the poem, welcome to Holland. It is such a great poem. It really helps you gain perspective that even though this is not the life that you dreamed about, it is still a life that's very, very beautiful.

00;14;24;04 - 00;14;47;17

Robin

It sort of describes the pregnancy. Like you're going, you know, you thought you were going to Italy, you ended up in Holland. But to be honest, I've been to both places now, figuratively. I've had twins that are perfectly healthy. And then I have Haley, who has multiple issues and even though both places are beautiful, I've learned so much more in Holland.

00;14;48;07 - 00;15;19;28

Robin

I've learned what's important. I've learned how to treat people, how to love people, how to be patient, how to be content and kind. All of those things. I don't know that I've learned all of that terribly in Italy, so I'm very thankful for that poem and for that lady speaking into my life. And I know for myself, I'm 20 years into this journey and I'm sort of going back and talking about the beginning times that really as fast forwarding.

00;15;19;28 - 00;15;47;29

Robin

I mean, she's been with me for 20 years now. It's a life that I wouldn't trade. It's a life that I would do all over again because it's just done so much good for our family, for my children. It's just such a wonderful person to be around. The things look different in our house compared to other families because we do always have to have someone here with Haley.

00;15;48;13 - 00;16;15;07

Robin

So it can be harder. Now, I do have twins, Maddie and Sloane. As I said, they're almost 14 now and this is all they've ever known. And we have always taught them to love and care about Haley. And not only Haley, but people like Haley. People that are weak in life that we are called to defend and step up or help.

00;16;15;29 - 00;16;39;28

Robin

And so in their own way, they even do things for Haley, like just turning on a favorite show. We taught them that serving Haley, that's helping Haley. There's many things that they do themselves just to help her. I know, Maddie, one of the things that she does is she cleans her face for her because she can't do it.

00;16;39;28 - 00;17;04;27

Robin

Like we used things to get the oil off her face and all that. She does that for Haley because she does that for herself. So there's things that they do that they show their love for Haley in that way, it can be difficult. Right now, our son is involved in baseball and middle school and practices or games or five days a week.

00;17;04;27 - 00;17;25;11

Robin

And so my husband and I share the responsibility in taking him either to the games or the practices we rotate. And someone always stays with Haley. And my daughter is signed up for band camp, which is also going to be aggressive schedule for about a month every single day, well, Monday through Friday. So we'll split it up that way.

00;17;25;11 - 00;17;49;17

Robin

And then we do have grandparents, thankfully, that are helping us take some of that load, taking them where they need to go because we do want them to have and enjoy their life as well. But things do look different, like vacations sometimes. Chuck will take Sloan out on a fishing trip, and I'll take Maddie to an amusement park where the other parent stays behind.

00;17;50;03 - 00;18;19;04

Robin

So our life definitely looks different. We can't just pick up and go on a vacation together, or I can't even pick up and go to Walmart if I need to. Everything has to be very planned. The things that we have learned together as a family, those things are because we live this life and we're just very thankful that we have been taught so much on this journey.

00;18;19;10 - 00;18;49;16

Robin

Like I said, through just caring about other people, one of the things that I focus a lot with my twins is on their character. I just know that by them having a sister like Haley, it's going to help them to go out into the world and be better people who can help other people. And so within the sovereignty of God, you can see why people like Haley are very much needed here, that we shouldn't discard them, that we should help them.

00;18;49;26 - 00;19;13;25

Robin

If you don't have a child like this and you're listening, be kind and help these people. Don't lose your sense of humanity. A lot of times people are just looking for empathy, compassion and kindness. And so if you walk up to me and you exhibit those very things about yourself, that's going to help me too. So that's how you can help.

00;19;14;28 - 00;19;23;05

Courtney

Robin, can you tell me how you care for Haley medically and what your relationship is like with her medical team and how you fostered that?

00;19;24;04 - 00;19;54;24

Robin

Just to explain a little bit about Haley, to give you a better picture of what life looks like in the Hampshire home, she uses a tube for feeding and hydration and she cannot walk or hold her head up on her own and has no son or gross motor skills. She's cast roughly four times a day on average, given about eight medications, and she uses a trilogy machine at night to assist her with breathing as she breathes very shallow.

00;19;54;24 - 00;20;19;23

Robin

Her day mainly consists of her morning, and her night routine are pretty aggressive with all the treatments that we're doing just giving her medication. Sometimes she requires breathing treatments. She is assisted in using the bathroom both ways. In the morning we do every single personal care item that you can think of in the morning. So the care is pretty intense throughout the day.

00;20;19;23 - 00;20;45;05

Robin

It's mainly caffeine giving, hydration, giving medications, and then the nighttime routine is pretty aggressive as well. So it is a full time job. It really is. But it's hit and miss during the day. So there's times that I can take a break. There's times that she'll be on her break and she'll watch her favorite shows. But it is a lot of care.

00;20;45;05 - 00;21;17;22

Robin

Her biggest obstacle is her health, and she's completely bed fast. And with her scoliosis getting increasingly worse, we don't travel with her anywhere. Both of her physicians come to the home and we are so thankful. And currently she is on hospice basically, we got hospice in the picture so that we could build a relationship with them. As the breathing issues became increasingly worse, we could just see signs that we really need to get them in the picture.

00;21;17;22 - 00;21;44;10

Robin

We need to build a relationship with them. So we have hospice to come in once every two weeks and they can evaluate her as well. I would say 90%, maybe 95% of any problems that we've ever had outside of her diagnosis has been medication related, and it's just figuring that out. We try to fix one thing and then we hurt another.

00;21;44;22 - 00;22;13;04

Robin

A couple of years ago, Haley started having really bad next spasms, and to combat that, we put her on a medication and it took us quite a nice dosage of that medication to get her really to where she was comfortable. And she seemed to do fine with it. But about six months later, she started acting druggy and didn't put it together fast because it was like a six month time period.

00;22;13;04 - 00;22;44;12

Robin

We have slowly tried to get her off of some of those drugs, but before we got her off the correct amount that we really need to, she started having all kinds of breathing issues so bad. For four months we had done back to back antibiotics and both doctors that we were dealing with a pulmonologist and our primary doctor, they both came to the house and said that they really felt that the only thing that they could do at this point would be comfort measures.

00;22;44;12 - 00;23;13;18

Robin

They just couldn't get things better with her breathing, she was requiring a 24 seven machine to help her to breathe. While we were waiting for hospice to come in, I just told my husband, Why don't we just try some things and we exited one dose of one drug, and within three days we saw her 80% better. And she was just right on the line of everything turning off.

00;23;13;18 - 00;23;51;29

Robin

Since as a day before yesterday she was all smiles, laughing. Yesterday I didn't have her on the machine at all during the day, but that one medication was greatly impacting her. So I think it's definitely something to look at always as a first, could there be anything that my child is on that could be causing these issues? I've had doctors ask me if I'm a nurse and I'll say no, but I do have my Ph.D. and Haley Hatcher, basically, I study her.

00;23;52;04 - 00;24;14;26

Robin

I pay attention from head to toe. I look at her facial expressions. And I also don't do more than one thing at a time. I can't recommend that enough. You know, when when you're trying to figure out what's going on with a nonverbal child, you really want to just do one thing at a time, wait three or four days and then do another thing.

00;24;15;04 - 00;24;41;18

Robin

Pay attention for her. What we do is we listen for normally her first step of being unhappy or trying to cope through something is grounding her time. And that that tells me normally she's in a lot of discomfort and it just I just have to narrow down where that's at. Normally it's a common place and I might have to re situate her past the grounding of the teeth.

00;24;41;23 - 00;25;06;11

Robin

She will if it's not taken care of, she'll have a seizure. The pain will tip her over and she'll have a seizure. And then she also can cry as well to exhibit pain again. There's so many things that I have figured out just by paying attention. Our most recent thing is she has acted what I would call more druggy.

00;25;06;24 - 00;25;29;01

Robin

She's just out of it and there shouldn't be really a reason because there's no we're not giving any more drugs because she's been on these same drugs for years. When you really start thinking about it critically, thinking about it, it made me think it's it's probably her kidneys or her liver. It's just not exiting out. And a blood test confirmed it was her liver.

00;25;30;01 - 00;25;54;16

Robin

The enzymes are very elevated, so it's just really paying attention and putting the clues together and working with a good team of people that as I tell them what's going on, they can help me put the puzzle pieces together. My dad will come over once a week and even though my dad really can't really do much for her, he can look after her.

00;25;54;18 - 00;26;16;00

Robin

And oftentimes I have him to come once a week and especially may have something going on that I need someone to sort of oversee her. My husband has been wonderful in this journey. You just you don't know who you've married until you have a child like this. And then I remember thinking we had her ten years into our marriage, our first child.

00;26;16;00 - 00;26;41;03

Robin

And I remember thinking how wonderful. Stick around for all this, because a lot of dads leave the divorce rates like 80% for a child that's this complex and but you know what? He has been the best dad ever. He intensely loves Hayley just as much as I do. And sort of our deal here is he works Monday through Thursday, but on Friday he gives me a break.

00;26;41;26 - 00;27;05;04

Robin

And so I enter the room some, but not much because I just need to basically get away. And that'll be the day that I'll go get groceries, that I'll take care of things occasionally I'll do something fun, but I do get that one mental break on Friday and I do have a rest that worker. But she doesn't really help me so much with Hayley.

00;27;05;04 - 00;27;32;07

Robin

She helps me with the stocking, crushing the medicines, washing syringes and things like that. She's like 72 years old, but the reason she is the best rest fit worker is she too had a child like this. Her child died about five years ago. And so she understands this life. She's not intimidated by it. But even at 72, she is still trying to make a difference.

00;27;32;07 - 00;28;11;01

Robin

And she is. And so once a week we get her. I don't have any nursing help, anything like that. We would like to, but it's just based on where we live. I think nurses are sort of hard to come by right now, but I'm just still very blessed with the help that I do have as far as working with the doctors, the biggest thing I could tell you as some advice and some wisdom is definitely always use sugar, you know, to the to the best that you can you sugar and only pour out the vinegar when you have to.

00;28;11;17 - 00;28;30;06

Robin

And that's how I've dealt with things. If I have to pour out the vinegar, I will do it. I have such a love for Haley, and that love makes me want to fight for her. In fact, I'll tell the doctors I'm going to fight to the death. And they all know that about me. One of the things that I have learned is respect is earned.

00;28;30;06 - 00;29;09;01

Robin

I don't ever cry wolf with the doctors. And so they do know that if I call them and say, this is what I see and this is what we really I think we really need to do 99% of the time those doctors agree with me. I have earned that respect with them. They know that I know her better and they have the wisdom to know that early on we did go through some doctors that didn't have that same wisdom and you could tell they were sort of hurting people through and you didn't really feel like they wanted to be part of this team.

00;29;09;16 - 00;29;34;27

Robin

And so therefore I just dropped them. So we really when you have someone as complex as Haley, you do need a group of people who are really paying attention. And they do look at me as the one who understands the most about her, and they see that for 20 years I have cared for her extremely well. So they do trust that I'm looking out for her best interest.

00;29;35;24 - 00;30;00;22

Robin

I remember we were in the hospital once and our regular doctor had to leave and he put another doctor in charge. And I didn't even know this doctor and he didn't know me. And he walked in and he said, Well, I guess you guys can leave now. And I was just floored. She was still having all kinds of issues and I tried to reason with him.

00;30;00;26 - 00;30;19;10

Robin

And again, he didn't know Haley, he didn't know anything about her. And he just kept insisting that he felt that she should that she should go home. And again, I'm 4 hours from home. So if there's problems, I've got to come back. And I really knew that I needed to fight there. I knew that things weren't just right.

00;30;19;12 - 00;30;44;01

Robin

She wasn't nearly back to her baseline, so I definitely had to pour out some vinegar with him and I had to get very stern. And we had words out in the hall and it was loud. And he ended up coming back to me and said, I am. I'm sorry. You're right. I didn't even look at her file before I came into the room.

00;30;44;25 - 00;31;14;29

Robin

That was one time that I really did have to advocate, but I do sort of have to laugh. Our service coordinator, who we have had now for about 15 years, she had told me that whoever my previous service coordinator was had told her, Yeah, you go ahead and take her. She's more difficult. And so when our news service coordinator started with us, I guess she had some reservations and thinking, Oh my gosh, what am I getting into?

00;31;15;09 - 00;31;39;17

Robin

But she said, You know what? I learned? You're not difficult. You're just an advocate. You advocate for your child. There's many sites in this world. It's very stressful in this world. I'm not going to I'm not going to lie. It's not so much with Haley. It's with all the outside stuff. It's all the things that you're fighting for, fighting with the school system.

00;31;39;25 - 00;32;03;16

Robin

Then you're fighting to get the supplies that you need or the equipment or the increase in the medication. You're constantly proving yourself and fighting and you sort of learn what's important to fight for and then what you should just let go of. And there's plenty of things I've had to let go of over the years just because I don't have I don't have it in me.

00;32;03;29 - 00;32;23;09

Robin

But you recover, you get better, and then you get back on your feet and then you start fighting again. And that's really what this looks like. I have built such a great team of people around me. They all help me fight too. We've just really been blessed with a great team.

00;32;23;09 - 00;32;42;16

Melina

So Robyn, that is something that has driven you to help change the way that other people receive treatment by helping to train medical students and health care students on the family perspective. And you've also written a book.

00;32;42;16 - 00;33;09;25

Robin

Yes, we started this book. One of my best friends, her name is Michelle Moran. We started this book almost five years ago. And I told her that I really felt that God was calling me to do it, to share my story. And I wondered if she would write the story for me because I'm not a writer. She is very eloquent and articulate in her writing.

00;33;10;12 - 00;33;49;09

Robin

So we jointly worked on this book for about five years. There was stops and starts along the way, but eventually about a year ago a publisher picked it up and it's called God Said No. Within the book, I just try to tell the story as to how God's saying no really benefited me. It's really a very transparent story that I tell the ups and the downs, not just with Haley, but within the marriage, having twins come on board, just really telling the real story.

00;33;49;24 - 00;34;11;03

Robin

But at the end, wrapping it up that God saying no to me is a beautiful word. It's a protective word. It may break your heart, but it can change your life. God's saying no is merciful, and it's His way of giving us something much better. All this heartache and this pain in the beginning, you just want it to stop.

00;34;11;03 - 00;34;39;22

Robin

And it didn't go away. God has allowed me to endure, but he's been there with me the whole time, helping me and holding my hand. And for me that has been what has helped me on my journey. It's a day to day walk and I think just realizing too that Haley will get a a perfect body one day where she won't struggle and there won't be any pain.

00;34;39;22 - 00;35;03;09

Robin

And living with that every day, just knowing that every day there is hope, that helps me tremendously. You know, our goal is never to make a dime on book. The whole agenda has always been that we could get it into the hands of those that need it. And especially, of course, my heart is towards the disabled community, the caregivers.

00;35;03;20 - 00;35;27;26

Robin

But outside of that, just anyone that's going through a fire in their life, this book will help them. You can apply the same things that I did to help you, so we're really excited. It is out and it's available now and it can be purchased at traditional brick and mortar bookstores at Amazon.com, Apple iTunes Store or Barnes and Noble.

00;35;27;26 - 00;35;49;05

Robin

So it's called God Said No. Why are the Fires of My Life Are Necessary? So we're really excited about it. In the back of the book, I do have my email address and if you ever want to connect with me, if you ever need encouragement or just to not feel alone, my email address is there and you can contact me that way.

00;35;49;05 - 00;35;56;10

Robin

And if by chance you can't afford a book, just reach out to me and we'll make sure that you get one.

00;35;57;19 - 00;36;04;20

Melina

We're going to have copies here for people to borrow through our linen library as well.

00;36;04;20 - 00;36;30;11

Robin

We have just learned let's just take it day by day. Yesterday was such a good day and Haley smiled and laughed and enjoyed life and going to appreciate that day. That's one of the things that can really impact parents when they look ahead into the future. And I just learned that I'm not even promised a tomorrow, I'm given today, and so I'm going to enjoy today.

00;36;30;11 - 00;36;54;13

Robin

And if we spend our whole life fretting about the future, you can't really enjoy today, I will say that Haley is doing much better. She's feeling better. She's breathing and she's happy. And I don't think I can ask for anything better than that. I hope that we'll stay on this track. It is a roller coaster ride with Haley.

00;36;54;13 - 00;37;14;21

Robin

It is. I know that I try to put on a smile, but yeah, on the inside I'm screaming at times you could pick me off of the floor at times, but you would never know because I've learned I can't sit and cry all the time. I just have to pick myself up. I have a family I have to take care of.

00;37;15;02 - 00;37;41;21

Robin

I have to be able to take care of Haley and I can't do that if I'm emotional all the time. So there's good days and there's bad days, of course, but the good definitely outweigh the bad. And that's why I can say I would do it all over again. I would do this exact journey all over again, take it day by day, and enjoy today.

00;37;42;21 - 00;38;09;19

Robin

Get a hold of the poem. Welcome to Holland and look at how your perspective can change. Enjoy this person. I tell people that really I need to be more like Haley rather than her being more like me. She's a beautiful person. There's really can be ugly things inside of me in my heart, but not for her. I would just enjoy being with this person.

00;38;09;19 - 00;38;33;15

Robin

And I'll also look at life through a different lens. Like, you know, how do we serve God on Earth? We serve God on Earth by serving other people. And so I enjoy serving Haley. I don't begrudge this life. She is the she needs help. And so I enjoy caring for her. There's love attached to all of that care.

00;38;33;15 - 00;39;01;15

Robin

So it can be very hard at times, but just take it day by day. I will tell you that if you could get a hold of the book, God said know it will tell you the whole story. And my biggest thing is that you don't feel alone, that you don't feel isolated. I think that's where we can really get stuck in this life doesn't have to be about despair and depression and anxiety.

00;39;01;15 - 00;39;29;02

Robin

There's many wonderful, beautiful things about this life. But you have to look through a different lens. You can't get caught up in the diagnosis and the day to day you have to look and appreciate that person for who they are. That's what we really see in Haley. She is such a huge part of our family and what God has done to change us, which was greatly needed.

00;39;29;02 - 00;39;58;24

Robin

You would think, how can a person that cannot speak a word have such an impact on people? But within the sovereignty of God, He can use these very people to impact us who are very flawed, who have lots of imperfections. But just to hang around a person like Haley is really a beautiful thing. And it has changed me forever and it has driven me to have a purpose.

00;39;58;24 - 00;40;20;14

Robin

And that purpose is to make this disabled community to not feel alone. In my part will be this book. It's just getting it in the hands of these parents that desperately need it that they're in the heat of the battle in those first couple of years. And they need to know that it's it's not always going to look like this.

00;40;20;14 - 00;40;54;25

Robin

I desperately want to show them what the other side looks like. I really settled more into this life. Around a year or two, I felt like God was telling me to settle in, that this wasn't going away, and I think that helped me a lot. I did read something, the Bible that really did help me and the verse in the Bible, Jeremiah 2911 where God is telling me I have a hope and a future for you and of course, all that sounds great.

00;40;54;25 - 00;41;18;25

Robin

But for the Israelites, even though he did tell them there's going to be a hope and a future for you, he was also telling them, you're going to stay here for about 70 years in exile. So in that 70 years, build houses, have children, go on with life. So that was going to be for 70 years. And for me, it's been 20 years.

00;41;19;11 - 00;41;37;27

Robin

And he he was telling me, settle in there was lots of things that you're going to learn here. There's going to be a hope and there's going to be a future for you. But for right now, this is where you are and this is where you're going to stay. And I think that once you come to that realization, it's going to help you.

00;41;38;09 - 00;42;22;00

Robin

If you're always just hoping and your begrudging your life that you want it to change and it's not changing. You're not going to enjoy every day and you're not going to have joy and happiness. But I settle in, I settled in. I know that's where I am many days, I'll be honest, it can sort of feel like I live in a prison because I don't leave my house much and I'm very thankful for the things that I get to do like this and like the project doc that I can do something outside of the house that sort of helps me feel like I'm making a difference, that really I am making a difference for this

00;42;22;00 - 00;42;53;05

Robin

little girl. I am impacting her and I'm helping her and I'm loving her. I would just say enjoy because time is going by fast. I can't even believe that Haley is 20 years old. It was like sometimes the moments went by so slow and the days seem to drag that times. But yet the years have flown by. And now I could be nearing the end of our journey and I grieve the loss of it.

00;42;54;15 - 00;43;11;14

Robin

I grieved at the beginning and now I'm grieving the loss so that as I have settled in, I've grown to love this life. And I know that you will too. But you do have to look at it through a different lens, just as I have.

00;43;13;15 - 00;43;29;03

Melina

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