

The Lovelight Stories[®]

PODCAST

Ep: 29 | Our Surprise Gift: How Our Son With Down Syndrome Has Grown Our Faith with Monica Mangiacapra | A Joyful Advocate | [SHOW TRANSCRIPT](#)

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00:01.70

Stephanie Jacobs

Monica, welcome to the Love Light Stories podcast. It is so great and such a joy to have you on here today.

00:08.73

Monica Mangiacapra

Hi, thanks so much for having me.

00:11.49

Stephanie Jacobs

Yes, so we were just talking about, it's really interesting, we met through Instagram. um We had done the documentary with my brother Jesse who has Down syndrome and he um they the stories made with love did a little documentary on him and you reached out and said, oh my gosh, this is so precious. I have a young son and this is what I envision and hope for my children's relationships to be one day. And I thought that was so, so sweet. So that's how we got connected for everyone listening. um And then you even sent my brother Jesse a book and my little Liam, my son a book of um a book that you've written. And we'll actually talk about that later. But it was so sweet of you. So anyway, just delighted to have you on the show.

00:58.98

Monica Mangiacapra

Well, thank you. I feel like it's a full circle moment. So I'm excited to get some time with you and learn more about you and and just the opportunity to share our story.

01:08.59

Stephanie Jacobs

Yes, and I think it is so special that you're willing to be sharing your story and advocating for others who have Down syndrome and other parents who have that diagnosis. And so but just as we get started, could you take us back to your birth diagnosis story and in help us understand what it felt like in that moment?

01:30.02

Monica Mangiacapra

Sure. So out my husband and I, you know, we've been together, I guess now almost 20 years, married almost 15, but, you know, rewind back almost three years ago. I was pregnant with my third and we were waiting to find out the gender. That's what we thought the big surprise was going to be. And I went in at my routine 37 week appointment They saw some complications, and not with the baby, but with me. And so we were rushed into the OR for an emergency C-section. And so all of that was very scary and unanticipated. And so, you know, in the ER, we

02:10.65

Monica Mangiacapra

We had an emergency c-section the baby came out crying, you know, that's the most beautiful sound when you have kind of a scary situation and After that everything was good God had a hedge of protection for us for sure that day because a lot of things could have gone wrong and and we were super fortunate and that they didn't and so after that delivery

02:14.77

Stephanie Jacobs

Yes.

02:30.68

Stephanie Jacobs

Wow.

02:34.18

Monica Mangiacapra

My husband and I were in the recovery room with our baby. We were so surprised to find out he was a boy and I, you know, really, for some reason thought it was going to be a girl. And so we were kind of, you know, in the recovery room, thinking of names. And I had asked my husband, Hey, can I see pictures?

02:51.98

Monica Mangiacapra

of the OR and he had sent me, he showed me pictures on his phone and I remember seeing pictures of Isaac and his eyes were very like squinty and I remember thinking, oh man, his eyes are so squinty but my eyes are kind of like that too, especially when I get excited and you know newborns are so squished anyways right out of the way.

03:12.25

Stephanie Jacobs

Yes.

03:13.37

Monica Mangiacapra

And so, you know, I just remember thinking that but I didn't say anything out loud. And I was holding Isaac and my husband, you know, very quietly just said, Hey, you know, can I see his hands? Let me see his ears. You know, he was asking me all these questions and specific questions on things he wanted to see on him. And I was like,

03:35.55

Monica Mangiacapra

What are you looking for? You know, obviously there was something he was looking for and he just very calmly said, you know, I think he has Down syndrome and as soon as he said that I Knew okay that 20 eyes, you know, that's it right?

03:48.43

Stephanie Jacobs

Ah.

03:53.03

Monica Mangiacapra

Like I think I Had he not been our third baby, we probably wouldn't have necessarily noticed it because they were very subtle.

03:57.75

Stephanie Jacobs

Mm-hmm.

04:00.82

Monica Mangiacapra

It wasn't something that we had anticipated. I had probably eight or nine sonic grams. you know, a very normal pregnancy, um a very just easier pregnancy.

04:13.11

Monica Mangiacapra

And so, you know, as soon as he said that, though, obviously having no understanding, no knowledge of down syndrome, it was a little bit of a shock, like, oh, wow, like this is unanticipated.

04:13.79

Stephanie Jacobs

Yeah.

04:27.05

Monica Mangiacapra

But in that moment, I think also because we had kind of gone through a traumatic birth, God just gave me this and

04:27.28

Stephanie Jacobs

Yes.

04:36.02

Monica Mangiacapra

just this, this piece. um And Psalm 139 was laid on my heart, you know, and I just knew, you know, God, this baby, this diagnosis, it was unexpected for us, but it is not unexpected to you.

04:50.60

Monica Mangiacapra

I believe that in my whole being that God created each one of us, just as we're supposed to be wired in our DNA and that extra chromosome was no mistake. And it was there intentionally and <unk> and

05:01.09
Stephanie Jacobs
Yes.

05:04.10
Monica Mangiacapra
If God had a purpose for that extra chromosome and for our sweet Isaac to be with us, then I was just going to hold on to that. And, you know, that was it.

05:12.25
Stephanie Jacobs
Wow.

05:12.67
Monica Mangiacapra
I really was not too scared. I think I was just, I went into research mode. You know, what try, what do I need to ask the doctors?

05:22.69
Monica Mangiacapra
What do we need to look out for? What should we try to expect? Um, and so that's kind of the mode I went into.

05:30.73
Stephanie Jacobs
Wow, that is incredible. First of all, i I just want to mention the fact that you and your husband recognized this and the doctors hadn't said anything. Is that right? That's what I'm hearing.

05:43.51
Monica Mangiacapra
Yeah, it was kind of wild. you know This was a major hospital um in North Dallas.

05:47.78
Stephanie Jacobs
Mm hmm.

05:49.68
Monica Mangiacapra
and you know We had a very great medical team. I don't want to fault the medical professionals for not saying anything. I think probably, and I've made this assumption, that most people probably get prenatal diagnos you know a prenatal testing.

06:03.93
Stephanie Jacobs
right

06:05.20
Monica Mangiacapra
And, you know, this was our third baby and I'm kind of a control freak. So from all my pregnancies, I always was just like, you know what, I'm just going to trust God. And, you know,

well what happens happens and we've never done prenatal testing. And so I think maybe they assumed.

06:23.43

Monica Mangiacapra

that we had had prenatal testing and that maybe we had some insight that that might have been a possibility.

06:27.74

Stephanie Jacobs

Right. Yep.

06:29.32

Monica Mangiacapra

When he was born, all his um his blood sugar, his weight, everything, you know, I think it's whatever that test is that they do right after the babies are born, his we're all perfect.

06:38.17

Stephanie Jacobs

Yep. The Apgar test or so.

06:39.82

Monica Mangiacapra

And yes, Apgar, that's right.

06:41.17

Stephanie Jacobs

Yes, yes, yes.

06:41.82

Monica Mangiacapra

Yeah, his Apgar scores were, I think, actually even maybe higher than my other babies. And so there was nothing concerning, even being three weeks early, he was still over seven pounds.

06:46.88

Stephanie Jacobs

Wow.

06:53.46

Monica Mangiacapra

So it's pretty incredible.

06:53.67

Stephanie Jacobs

That's incredible. Yes, that is incredible because my son was like about three and a half close to four weeks early and he had to be in the NICU for 19 days, you know, he really struggled.

07:05.62

Monica Mangiacapra

Yeah.

07:06.76

Stephanie Jacobs

And so to have a baby with Down syndrome that was doing so well, because there's a lot of things that babies with Down syndrome can struggle with right away. is um Heart defects, right heart murmurs, and different things. and um Anyway, that's incredible. I would love to um dig into the fact too that you had such peace so early on.

07:31.80

Stephanie Jacobs

and such like trust in God and strengthen that because just hearing in hearing a lot of stories that I know you know people that have come to my family um you probably can attest to this but once you have a child with Down syndrome others who are going through that same diagnosis early on um often reach out to other parents which is a beautiful blessing to be able to do that and be there first for others and so I've watched over the years um my parents get to do that for others in our community and often the reaction including my parents was like oh my gosh like what does this mean I'm scared or having trouble accepting it or

08:07.47

Monica Mangiacapra

Mm hmm.

08:11.14

Stephanie Jacobs

whatever that might be because ultimately we often have the fear of the unknown, right? And I think it's just such a testament to your faith in God and your trust and um just that motherly instinct of like, okay, we can get through this and I love you and you're my child and um we will we will get through this.

08:15.71

Monica Mangiacapra

Yeah.

08:32.21

Stephanie Jacobs

And so anyway, I just want to mention that because that's pretty incredible from the get go.

08:38.20

Monica Mangiacapra

Yeah, it was a it's a huge blessing. I mean, not to say that it's always been easy because you have peace, but it certainly you know has made the biggest difference from the very beginning.

08:49.76

Stephanie Jacobs

Yeah, yeah, that's wonderful. Well, for those listening who maybe are going through a similar diagnosis, um I guess you're such a strong light in that way. So ah thank you for that. So can you just share a little bit too about the daily joys and also the difficulties of raising Isaac and, um you know, any little stories that you have to help shed light on that?

09:14.36

Monica Mangiacapra

Sure. You know, I think from the get go, I think what Isaac has kind of taught us is that, you know, particularly when you're thinking of medical things, I think right in that recovery room, we were Googling, you know, Down syndrome and you see, oh, the heart defects and you see the sleep apnea and you see all these really scary things. And from the very beginning, Isaac was very much not fitting that mold. And so it was almost like right away as his parents were like, OK,

09:42.34

Monica Mangiacapra

you can be aware and you can be educated but know at the end of the day it's going to be whatever God's will is for Isaac. So and I know that's not the case for every child or kid with Down syndrome, right? Everybody is so different and so you know obviously there are things that are more challenging when he was seven months He had infantile spasms, which is pretty rare. and The percentage of children who have infantile spasms are higher with kids with Down syndrome. And so that was a really scary thing. But, you know, going back to that Down syndrome community, because I had

10:22.27

Monica Mangiacapra

ah community of moms who have gone through that I was able to reach out to them they were able to help me with talking to doctors and getting what we needed to get him diagnosed and so that was scary you know just knowing like okay you know what if he doesn't heal you know what if he had I saw families that had spasms for years and years and I

10:38.42

Stephanie Jacobs

Mm hmm. Mm hmm.

10:45.30

Stephanie Jacobs

Can you just to ask, can you describe infantile spasms for anyone who doesn't know what that is?

10:51.56

Monica Mangiacapra

Sure. So infantile spasms is a type of seizure and it often very, it's very hard to diagnose because oftentimes it looks like a startle reflex. So, you know, when you have a new baby and especially when they're brand new and like maybe they're used to being in the womb or being swaddled or you take the swaddle out and their arms kind of like well you know, go out.

11:00.96

Stephanie Jacobs

Okay.

11:10.56

Stephanie Jacobs

Mm-hmm.

11:12.10

Monica Mangiacapra

And so it's very quickly. And so infantile spasms kind of look like that. Their arms kind of go out and then their knees kind of go up all at the same time, very simultaneously in kind of a jerky motion.

11:24.33

Monica Mangiacapra

And sometimes they can only do that once um Isaac ah started doing them in repeated motion. And so that's how I knew the very first time we saw him do it, we actually thought he had the hiccups because it was so arithmetic.

11:37.91

Monica Mangiacapra

and but then he did it later that night and I was like hold on this is this is weird but he didn't cry he didn't seem like he was in pain so it was very deceiving but because of that community somebody had posted videos of their child doing it and I was like that's it that is what he's doing and so I was able to video him and get with our geneticist and they kind of fast tracked us to the neurology and get the testing And so those things with each episode, it can cause brain damage, life altering brain damage. So it's very scary. um you know And so that was one of the things that too, like even now we were really fortunate that we were able to diagnose it and treat it. And he has not had, he's been seizure free. He's about to turn three. And so he's been seizure free for almost two and a half years now.

12:26.69

Stephanie Jacobs

Wow.

12:26.86

Monica Mangiacapra

and he hasn't had any relapse but that's a hard thing to also you know just in the back of my mind hey he could relapse or he could be susceptible to more seizures but I have to be very intentional and not letting it steal my joy right now and be in that constant state of fear but just give it to the Lord hey Lord I know you got him and I'm gonna just bull believe that he's fine right now and if that's something that we hit down the road

12:35.72

Stephanie Jacobs

Yeah.

12:53.43

Monica Mangiacapra

then we'll do that when it's when it happens right um and so those have been some some hard things you know navigating the medical field with your child and but then also just the joy and that resilience like it's so motivating to me to see Isaac and even all these things that he's had to go through like the spasms or just

12:56.19

Stephanie Jacobs

Right, right, yes.

13:15.23

Monica Mangiacapra

the daily therapy, physical therapy, occupational therapy, speech therapy. We have so many therapies. And you know just yesterday, he took his first two steps by himself.

13:26.32

Stephanie Jacobs

oh wow

13:27.06

Monica Mangiacapra

And so that's amazing. you know I think it's so hard to, I think as parents, regardless if you have a child with a disability, is you find yourself comparing, right?

13:37.99

Stephanie Jacobs

who

13:38.65

Monica Mangiacapra

You know, my kids walking at this point or my kids talking and, you know, multi sentences or whatever. It's very hard, especially with social media, not to compare. And that has been kind of hard for me, too.

13:51.01

Monica Mangiacapra

And, you know, Isaac's almost three and he's not walking. And so.

13:53.84

Stephanie Jacobs

Oh, wow.

13:54.30

Monica Mangiacapra

that's hard but he's also saying a lot of words and he signs and so it's just knowing that when he's time it's time and then when we hit those milestones man it is like such a joy and big celebration and not just for me but for Isaac and for my kids like it is a big cheering session for Isaac pretty much all the time in our house.

14:15.89

Stephanie Jacobs

Yes well I can imagine too like what that joy and pride um does for your children as they're growing up alongside of Isaac and just how that shapes them because I remember you know growing up with my brother Jesse who has Down syndrome he's two years younger younger than me and I've always had this like special like love and pride and just like wanting to cheer him on and all of that. And so I imagine your children getting to cheer him on in those big milestones must be really special as well.

14:52.26

Monica Mangiacapra

It is so special. And you know, it's so amazing to see me, my older kids are eight and five. So there's about two years difference between our middle son and Isaac, and then five years difference between our oldest and Isaac.

15:06.57

Monica Mangiacapra

And they're his biggest motivators. You know, like if I can't get him to do something or the therapist can't do it, we'll bring in Lily or Louie and they can motivate him and he'll do it for them.

15:09.56

Stephanie Jacobs

Oh.

15:17.08

Monica Mangiacapra

And it's just amazing.

15:17.44

Stephanie Jacobs

Oh, that is so precious. That is a yes. I love that. how How else like is Isaac's life positively impacting your children or just like, what are they, what is he teaching your other children and how are they coming to, to learn about the world and, um, love and acceptance, I guess.

15:38.92

Monica Mangiacapra

Yeah, I think it's been really interesting I think to like it was such a pivotal moment also in that recovery room. You know, as a mom, when you welcome a new baby, when a family welcomes a new baby, you're always like, okay, now we're going to have another kid. It's going to change our family dynamics, but nobody, I don't think really anticipates, Oh, now we're going to throw in disability in there and a disability we know nothing about. And so I remember thinking, Oh my goodness, like, is this going to be really hard for Lily and Louie? Is this going to be more attention away from them or are they going to resent their brother?

16:15.43

Monica Mangiacapra

You know, all these things that intrusive thoughts that kind of get in your mind of all the what ifs, right? You think worst case scenario.

16:22.45

Stephanie Jacobs

Yeah.

16:22.94

Monica Mangiacapra

And so to see it now here three years in the future or from that moment, you know, Lily, she's our oldest. She's always been very empathetic.

16:33.24

Monica Mangiacapra

She's our mini mama. We call her mini mama because she is that to her little brothers. But she is so aware of just other kids too, you know, in school.

16:42.76

Stephanie Jacobs

Hmm.

16:44.12

Monica Mangiacapra

She sees when there's a kid that doesn't have somebody to play with.

16:49.44

Stephanie Jacobs

Yeah.

16:49.42

Monica Mangiacapra

or she's very good at reading people's emotions and nonverbal communication because she does that for her brother at home.

16:56.44

Stephanie Jacobs

Yes.

16:56.57

Monica Mangiacapra

And so if somebody's having a hard time at school or sad, you know she will do her best to just go up and you know console that that kid or even just sit with them like she's just got the sweetest spirit and that just oh overall awareness.

17:13.34

Monica Mangiacapra

And so to see that also in just like her school, And her friend's dynamic is pretty special. And I see it with her little brother too. She does it at home. So, you know, wherever she goes, that happens too. And for our son too, you know, he's a boy. He's very rough and tough, but with Isaac, he, you know, they wrestle and he's, you know, my my middle kid is is a little small too. And so there's probably less than 10 pounds difference between

17:41.62

Stephanie Jacobs

Oh.

17:41.61

Monica Mangiacapra

him and Isaac and they wrestle and it's just they have this most amazing just special bond you know and I think too going back to teaching children you know even this last weekend when we were going through sickness you know having those hard conversations and saying hey like you know we might have to make a visit to the hospital or to the doctor to get them to listen to your brother's lungs to make sure he's got enough oxygen or whatever

17:46.26

Stephanie Jacobs

Mm-hmm.

18:08.46

Monica Mangiacapra

you know those are conversations that obviously nobody likes to have with their five and eight year old but we have them and they understand and we pray out loud together and i think it's also taught them like you know there's some hard stuff in this world and it's not always full of joy

but it can be it can be really hard and it's hard for mommy too and so let's just all pray really you know pray together and seek god's wisdom and comfort

18:08.55

Stephanie Jacobs

Yeah.

18:26.58

Stephanie Jacobs

who Yes.

18:34.33

Monica Mangiacapra

And that's where our faith lies with that and whatever it comes. And so it's just a very tangible almost everyday opportunities to have those conversations with the hard to.

18:44.19

Stephanie Jacobs

Yes, I love that. and And to summarize what I hear you saying too is just that having Isaac in your life has taught your family to really live with your heart on your sleeve and like be open and have this deeper faith that you walk out daily and it's not negatively impacting your children. It's really um helping to shape your children into being kingdom minded and have true faith and like caring about others and noticing and being empathetic of those around them.

19:17.82

Stephanie Jacobs

And um I think that is such an encouragement to others who may be feeling some of those similar feelings right away, like, Oh my gosh, how is this going to affect my children?

19:28.90

Stephanie Jacobs

And I think, you know, I've, I've seen many times other people too, when they have their second child, even though they don't have a disability, they have that fear right away, right? But what they're, Days from going into the hospital saying like oh these are the last few days with my first child Like how is this going to impact them and and all that and I think that's such a natural inclination and I can only imagine when you have a diagnosis that you don't understand how much that's amplified those thoughts and feelings can be amplified and so I just hope that this hearing that from you is such an encouragement to those who who might be feeling those feelings um and I can say too just from my own experience and of course I was young and I I remember some of it but this is just what others like my parents have told me and that I too was the girl who like always went and talked to someone who is crying feeling left out at the the table at school or at recess or you know just checking on people and how they feel and I noticed that

19:39.56

Monica Mangiacapra

Yeah.

19:58.95

Monica Mangiacapra

Right.

20:37.18

Stephanie Jacobs

And I always say that is because of my brother Jesse. Like I know that because you're just, that's just your entire environment growing up, right? You're just always checking in and you're noticing and you're supporting and you're cheering them on and

20:47.50

Monica Mangiacapra

Yeah.

20:53.97

Stephanie Jacobs

it shapes you into a different person. And I've said many times, he is a big reason why I'm doing the work that I'm doing today. And this podcast focuses on empathy and and love and acceptance and understanding these different issues we deal with of humanity. And a big part of that is Jesse. like And so anyway, I'm just echoing that same sentiment and what you're seeing with your daughter. and um We're not perfect.

21:24.94

Stephanie Jacobs

I'm not trying to say like, like, Oh my gosh to my horn here.

21:25.89

Monica Mangiacapra

Sure.

21:29.42

Stephanie Jacobs

I'm just trying to relay that message that it really is. I've been impacted by my brother in a similar way as to what you're describing your daughter. um So anyway, I think it's just really,

21:41.77

Stephanie Jacobs

exciting and incredible how much of a gift um people at Down syndrome are and and um there's a group it's just I guess you can help me explain it too but it's just kind of this um this pride of being like yes we have someone in our life who has Down syndrome and we have that love and joy and we are the lucky few and I i think I've seen you um hashtag that on Instagram before and talk about that and um It's really kind of just special to be part of that group, right?

22:15.47

Monica Mangiacapra

Yeah, yeah, absolutely, absolutely.

22:18.84

Stephanie Jacobs

Okay, so how about share a little bit about how Isaac has impacted your marriage with your husband.

22:26.92

Monica Mangiacapra

Yeah, so, you know, my husband and I were high school sweethearts. And so, you know, and we waited a while before we had any children. And so I think with Isaac, you know, I think the stat, I could be wrong, but I think it's between 70 and 80% of all marriages and in divorce.

22:44.82

Monica Mangiacapra

when they have a child with a disability. And so I think that's for a variety of reasons.

22:47.53

Stephanie Jacobs

Wow.

22:50.80

Monica Mangiacapra

I think when you have a child who has a disability, you know, there's just a lot more complications there when it comes to school or just life in general, right?

23:01.59

Monica Mangiacapra

How to support your child. and your family. And I think the added, um you know, the added attention that probably most moms are gonna give their child with a disability just by default. And sometimes that can have a negative impact on your marriage. And so my husband has been a strength for me and for our marriage. You know, he is very logical. He is very calm. He's super smart.

23:33.54

Monica Mangiacapra

he has amazing faith and so when there have been times where I have been like oh my goodness what if this you know and and you go down these like all these what-ifs um scenarios he has been like hey you know like let's just take a breath let's just see what happens, we don't need to freak out because that's not even happened, let's not freak out ah about something that might not happen, right?

24:00.77

Stephanie Jacobs

yeah Yes, yes.

24:01.41

Monica Mangiacapra

And so I think it has brought us closer and just also better communicating how we can better communicate what we're feeling, our goals for our family, our goals for each one of our children, and you know also that accountability within keeping our faith strong and keeping that like the forefront of our family too.

24:23.96

Stephanie Jacobs

Yes, that's really beautiful. And what a gift to have a husband that can be so strong and supportive and and you as well. I mean, I think everyone listening can tell or at least I do like how um ah strong in your faith you are and how you really walk by faith and also just your heart and where you're at and that you really are an active and involved mother.

24:47.85

Stephanie Jacobs

And i i can imagine like God really was designing that in that marriage. And that's, that's a really beautiful thing and and just such a gift for your children. So I love that so much. And you're talking about your faith in general, like how has Isaac, like what has he taught you about your faith or how has, I know we've talked quite a bit about your faith already, but is there anything else you want to say as far as how, um,

25:15.41

Stephanie Jacobs

much you've had to grow in your faith through the experiences with him or anything like that.

25:21.50

Monica Mangiacapra

Sure. I think, you know, with each child, you know, particularly as a mother, you're kind of forced to let go, right? You want to control so many things, but it's just not possible. Our children are each created with their own personalities and their own gifts and their own talents and also their own challenges. And so, you know, now multiply that by three, specifically with Isaac. And, you know, I have really, I think because of all the you know it's funny even with typical children you don't know what is going to happen in the future right like they could be sick they could get yeah they could get sick they could have an accident that you just don't know what's going to happen but for whatever reason families within the disability community

26:10.50

Monica Mangiacapra

particularly when you get a disability at birth. It's like we all of us said it, are so fearful for everything in their future. And it's like, well, we don't know regardless if it was a typical child or just a child with a disability.

26:18.39

Stephanie Jacobs

Mm hmm. Hmm.

26:24.23

Monica Mangiacapra

And so I think also just being much more aware and just being like, Lord, you know, I i don't know. i i don't know. And I will never know, right?

26:34.64

Monica Mangiacapra

I think it's brought intimacy with Christ out of necessity because the other I guess the other side of that would be complete fear.

26:48.45

Stephanie Jacobs

Yeah.

26:48.51

Monica Mangiacapra

And I don't want a mother like that. I don't want to live like that. I don't have the anxiety for that.

26:54.42

Stephanie Jacobs

Yes.

26:54.42

Monica Mangiacapra

um And so I think just knowing that I will not know and I think maybe also the understanding of hardships in this life like I often hear a lot of people say like well why do good things happen or why do bad things happen right like

27:12.98

Stephanie Jacobs

yeah yeah.

27:15.02

Monica Mangiacapra

There are all these really hard things in life. And it you know if your God was so good, why are these bad things happening? And Johnny Eric Zentada has one of my favorite quotes.

27:25.43

Monica Mangiacapra

And she says, God allows things or god but is god allows things he hates to accomplish what he loves.

27:36.16

Stephanie Jacobs

Oh, that's beautiful.

27:37.00

Monica Mangiacapra

And I love that so much because there's so much truth in it, right? Like it can be a horrible situation, right? But through that horrible situation might bring somebody to pray for somebody or even pray for the first time because

27:52.93

Stephanie Jacobs

Yes.

27:54.11

Monica Mangiacapra

They just don't have anything else to do, right?

27:56.53

Stephanie Jacobs

yes

27:56.80

Monica Mangiacapra

And so through those bad things, you know, God's bringing more people into his kingdom. And so I just often have to remind myself, you know, even if it's really uncomfortable or really horrible.

28:10.90

Monica Mangiacapra

There is good things that will come with this. Maybe not even in my lifetime. It might be in my kid's generation or my grandkids generation. Things that I won't see this side of heaven, but we will see it in heaven one day.

28:23.51

Stephanie Jacobs

Mm-hmm Yes, what an encouragement and and I even feel that encouragement as being a new mom, right?

28:23.79

Monica Mangiacapra

We'll see the fruits of that, that hardship. And so I think just having that to like really lean into God and being like, okay, God, I am trusting you. I don't like it, but I'm going with you, God.

28:36.52

Monica Mangiacapra

So.

28:42.78

Stephanie Jacobs

um Just there truly is so much you do have to let go and I have so much more to do but the you know just to hear you say like how you've wrestled with that or essentially not wrestled with that, you found peace in that through through that mindset and and that faith. So that's really, really beautiful. And I wrote down too, after our initial conversation, um just that your faith has in is informed by your experience with Isaac, but yet your experience with Isaac is has also formed your faith.

29:15.24

Stephanie Jacobs

which I think is just such a ah beautiful um outcome or not outcome, but a beautiful process, you could say. So that's really pretty. And as we're talking about faith, I know you shared with me a little bit about how you've struggled to find resources in a local church for your family.

29:36.05

Stephanie Jacobs

or sorry not for your family but for Isaac and um can you just share a little bit about that because I think um others might be going through that too and and really what you found in doing that.

29:46.84

Monica Mangiacapra

sure you Sure. So it's interesting how God has planted the seeds for years and years and years. And so before Isaac was born, I was able to volunteer at a church um within their children's ministry. And in that church, they had a disability ministry. And it was it was amazing, right? They were actively part of the congregation in the church.

30:08.47

Monica Mangiacapra

And so I got to volunteer beside that were you know that ministry for seven years, almost eight years.

30:14.79

Stephanie Jacobs

Mhm.

30:15.98

Monica Mangiacapra

And so when we moved, we moved at cities into a much smaller city than where we were living. And then Isaac was born. And so, you know, early moments again, when you go into mom mode and you start researching like, okay, how am I going to navigate this, how am I going to, you know, I guess just prepare, right?

30:35.21

Stephanie Jacobs

Yeah.

30:35.78

Monica Mangiacapra

I started looking for a church that had a disability ministry and I found, and unfortunately in our community, there were not really any churches that were serving the disability community.

30:47.35

Monica Mangiacapra

And I would talk to churches and several of them are like, you know, well, we don't have the resources or we don't have the finances or we don't have any families with disabilities. And I would always counter that and say, if your church does not have families with disabilities, birth through adult, then they're not there's a reason.

31:10.01

Monica Mangiacapra

right And I found out the stat is one in four children have some type of developmental disability, one in six adults have some type of disability, and one in three families leave the church due to their their them not feeling like their child is safe.

31:29.20

Monica Mangiacapra

or served with a disability. And so the ripple impacts on families with disabilities is that they're not in church, which means their siblings are not in church, the parents are not in church, and that the ramifications of that, right?

31:43.59

Monica Mangiacapra

I think for us, it was a non-negotiable that we were in church um for all of our families, for our older kids, for my husband and I, for our marriage, to have that community of believers and prayer warriors beside us.

31:44.23

Stephanie Jacobs

Right.

31:57.64

Monica Mangiacapra

And so I was able to get training. There are two organizations that I specifically love to give a shout out to. One of them is Johnny and Friends, and the other one is called With Ministries. Both of those are nonprofits. They serve all over the United States. Johnny and Friends is actually global.

32:15.83

Monica Mangiacapra

And so they do work in other countries too, but they come become alongside churches and give them resources and trainings for their volunteers and their staff so that they can better serve children and adults with disabilities within their church. And so, you know, this was something that I worked with for, I guess, going on two years now. And I'm so excited to, as of last December, one of our large local churches have have partnered, and I guess not even partnered with me, but partnered with, you know, with Ministries and Johnny and Friends to make this initiative for our church.

32:52.27

Monica Mangiacapra

And it's just so exciting because they're like, yes, we we see this as a need. We see this as a commandment. And in the Bible, it's very clear that they call the church to serve the disabled.

33:03.46

Stephanie Jacobs

Yes.

33:03.47

Monica Mangiacapra

And so we need to kind of give resources to these churches. And I just want to encourage parents If you're going to a church and you're like, man, I feel like they need more resources, there are organizations like these two that give resources for free.

33:17.40

Stephanie Jacobs

who

33:17.38

Monica Mangiacapra

And and that's where their ministry is. and And you can very much be the connector for that, for your family, but then also the the greater disability community.

33:27.25

Stephanie Jacobs

Right? And what a gift to have someone like you who says, hey, this is overlooked. We need to do something about it. And you're you're bringing it to the church's attention, which they might not fully understand the need themselves. And you as a mom who who's looking for this says, hey, I'm going to be an advocate for the advocate for this. and And just think of the number of families and people you're helping connect. and I mean, eternal.

33:57.17

Stephanie Jacobs

redemption and salvation and kingdom mindedness that so many families can now access just from, you know, one person saying, Hey, let's do something about this and I want to connect you and make this possible. I mean, that those statistics you shared are, are big statistics and, and so really,

34:19.31

Stephanie Jacobs

you know, it's an ending that the ripple effect that that can have. So that's wonderful. Thank you so much for sharing those resources. I will definitely link those in the show notes for any other families who are wanting to to be that connector. That's wonderful. So and you're also just a connector and such an advocate on so many levels. um Like I said, we connected through Instagram. You have um a platform called a joyful advocate.

34:45.80

Stephanie Jacobs

Can you just share a little bit about that as well as your book Different by Design, which again, you sent a couple copies of one for my brother Jesse, which was so sweet.

34:51.36

Monica Mangiacapra

Yes.

34:55.89

Stephanie Jacobs

um So yes, just share a little bit about all of that.

34:59.33

Monica Mangiacapra

Sure. So I mean, it's mainly just my Instagram handle, you know, for Facebook, I think. You know, I'd never really thought about what an advocate is prior to Isaac's birth.

35:11.36

Monica Mangiacapra

And I think once he was born and we were kind of catapulted into this new world, you know, you're like, okay, well, mothers, all mothers are advocates for their children.

35:11.70

Stephanie Jacobs

Mm hmm.

35:23.44

Monica Mangiacapra

And, you you know, but I wanted, I think sometimes advocacy can get, have, you know, I don't want to say like a depressing or negative aspects, but it does kind of feel like you're always in a fight.

35:35.75

Monica Mangiacapra

And I didn't want that. I didn't want to oppose advocacy. Yes, you are you know standing up and fighting for your child and advocating for them, but like we can also do that in a positive and joyful way. And a lot of times that's just by educating. It's not because people you know are

looking down or because they you know are out to do the wrong things or whatever. A lot of times it's just because they have not had the opportunity or the education To develop that awareness, right?

36:06.63

Stephanie Jacobs

Right.

36:06.88

Monica Mangiacapra

And so that's just kind of what I was I'm doing I am wrote different by design.

36:11.95

Stephanie Jacobs

Yes!

36:12.47

Monica Mangiacapra

I have a copy here, too um You know, it's it's funny how God opens those doors, you know Like I said when in the recovery room when he gave me someone 39 I feel like that is such a verse that so many people know right know and love and And when I was in the hospital, I was looking for books because I was like, all right, how are we going to explain this to my older kids that Isaac will be different?

36:39.26

Monica Mangiacapra

But I don't want it to be in a negative thing. I don't even want it to say like Down syndrome, right? Because what I was looking online and social media, every person with Down syndrome is different.

36:50.00

Monica Mangiacapra

And so I don't want to completely categorize him. And so and I wanted a children's book that had illustrations of all different kinds of disabilities and um different physical features, different vision, different hearing, different communication, different mobility, I wanted all those things.

37:06.20

Stephanie Jacobs

Mm-hmm Wow.

37:06.56

Monica Mangiacapra

And I could not find a book that had these illustrations. And I also can I might be able to find a book with like a wheelchair or maybe some like braces or something like that. um But none of those books had scripture in them. And I wanted a book with scripture. And so I, you know, kind of argued with God for a good year. Like, Lord, I don't know how to draw a stick figure. How am I supposed to make a children's book with all these cool illustrations that's in my mind?

37:34.34

Monica Mangiacapra

And he kept prompting me like just do it Monica. So I wrote it all out and then I went to Instagram actually, and you know through the God's grace I was connected to an illustrator who lives in Nashville, and she had done multiple Christian children's books, and I just randomly DM'd her and was like, hey, I have this manuscript. Would you be interested in doing illustrations for it? And she was so amazing. She did all the illustrations. We worked together. We self-published and, ah you know, the way.

38:07.42

Monica Mangiacapra

that has opened up conversations for other families. There's also disability prompts in the back of the book on how to talk to your kids about disabilities to kind of continue that conversation.

38:12.22

Stephanie Jacobs

Hmm. Hmm.

38:19.03

Monica Mangiacapra

There's some prayers and there's also two pages of disability resources for families if they need some more. resources and so that I actually just signed a contract for my second children's book and so hopefully that will be coming out that's with the publisher so that's really exciting um and that book is going to be on grief which is another ah hard topic but one that I think is necessary when talking to our kids and so that I'll be coming out I think later this year early next year.

38:30.81

Stephanie Jacobs

Oh my gosh.

38:46.77

Stephanie Jacobs

Wow, that is so incredible. And I just, as you were talking about this, again, that same thread of saying, hey, there's kind of this gap here that others who haven't walked through what I'm walking through wouldn't even know about, right? But because you're having this lived experience, you're saying, I'm looking for this resource. I'm not seeing it. So let's create it. And you're doing that with the book. You're doing that with the resources, with the church. um I think that's really beautiful. and And I've often thought many times, you know,

39:15.54

Stephanie Jacobs

that God gives the gift, I say a gift of Down syndrome to families. I know why I know you know why I say gift because it is truly a gift. i Absolute incredible experience and it comes with challenges like you said, but you gain so much more. um and He gives the gift of Down syndrome to families that I think can further his purposes in his kingdom through that those experiences and um I just see that in you and your family and it is just such a Honor and privilege to have this conversation with you um You know, I've I've often like pictured being able to have these types of conversations on the love light stories podcast because I As I just said, having someone with Down syndrome in your family is something that others can't possibly fully understand unless they're walking that that path, right? and the next path

40:21.72

Stephanie Jacobs

next best thing is to hear those stories from people that are and really um understand their heart and in those um Experiences and so I just thank you for sharing your heart sharing your faith with us all of the encouragement um that you're offering others who might be walking through something similar and um Just thank you so much. So before we wrap up I'd like to ask you what would you say to someone who's currently wrestling perhaps wrestling with a Down syndrome diagnosis and how would you encourage them?

40:57.65

Monica Mangiacapra

I would just say that just be ready. Just be ready to have a lifetime full of surprises and joys.

41:08.77

Monica Mangiacapra

And I think with hardship, because of the hardship, the joys are that much brighter.

41:15.39

Stephanie Jacobs

yeah

41:16.06

Monica Mangiacapra

And It is incredible to see that joy and to see that celebration and to see that resiliency that it will ripple through your entire family in the best and most beautiful way. And it will be with its challenges, but those challenges are so worth it. It's so worth it. It'll be the best adventure, I think.

41:43.12

Monica Mangiacapra

and And you'll be can you'll be able to connect with people you would never have connected with otherwise and opportunities that you would not have had without them. I think with Isaac, what what always surprises me is anytime we're anywhere, he's like a magnet to everybody. He just makes everybody laugh and smile. And even when he's not in the best mood, people are just drawn to him.

42:12.29

Monica Mangiacapra

And it just lifts your spirits, right? Even in those challenging times, you can look at them and they're just they're still happy.

42:15.11

Stephanie Jacobs

Yeah.

42:19.10

Monica Mangiacapra

And if they can be happy when they're going through all these hard things, then we can too. And itll it's gonna be okay.

42:27.17

Stephanie Jacobs

Yeah, I love that so much to learn so much that they have the potential to teach us too. and And that's beautiful. So Monica, this has just been lovely. Thank you so much for joining me today on the Love Light Stories podcast.

42:41.05

Monica Mangiacapra

Thanks for having me.