A Father's Journey - Navigating Life with Josiah

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Guest: Dr. Bobby Kern

Resources: Oklahoma Christian University | Directory - Bobby Kern

Don Drew: 0:29

Welcome to Peaceful Life Radio, your place on the internet for cultivating a peaceful life. I'm Don Drew and I'm here with David Lowry. Hi, Dave.

David Lowry: 0:38

Hi. How you doing today?

Don Drew: 0:39

Doing great, man. And we're here to help you navigate life's challenges with confidence and calm by getting rid of interpersonal drama and conflict and all kinds of other problems. Today, we have a very special guest, Dr. Bobby Kern, a university professor of family studies and the parent of a child with Down Syndrome. Dr. Kern's story is one of inspiration, resilience, and finding peace in the face of adversity. As the parent of a special needs child, he's He has navigated the challenges of raising a child with Down Syndrome from coping with the initial diagnosis to advocating for his child's needs within the healthcare and education systems. Through it all, Dr. Kern has maintained a sense of hope, inner peace, and an unwavering commitment to celebrating his child's unique strengths and abilities. His insights and experiences will undoubtedly provide valuable guidance and encouragement to our listeners who may be facing their own difficult life circumstances.

David Lowry: 1:34

I look forward to hearing your story, Dr. Kern. It's one that I've been wanting to hear for a while. But before we begin, we want to encourage our listeners to download, like, and subscribe to our podcast, Peaceful Life Radio. It only takes a moment and it will do us a lot of good.

Don Drew: 1:50

So, Bobby, tell us your story.

Bobby Kern: 1:52

Let's see. In February of 2013, we were expecting our second child because my wife was going to be 35 when she delivered. They considered her a high risk pregnancy. And we had to do a lot of the high risk testing. We went in on a Tuesday. I remember this day very well because I had just given a lecture in my 8 a. m. developmental psychology class on chromosomal and genetic abnormalities.

Don Drew: 2:20

Wow.

Bobby Kern: 2:21

I'd actually lectured on Down Syndrome that morning from a developmental perspective. After that class, around 11 o'clock, we went to our doctor's appointment. We weren't thinking anything other than routine. We found out in about a thirty second time span that we were having a boy, that he had Down Syndrome, and then were asked if we wanted to consider terminating the pregnancy.

David Lowry: 2:42

Oh my goodness. So, you went from knowledge and theoretical understanding to reality really quickly.

Bobby Kern: 2:49

Yeah, just like that. And it was humbling. There was a sense of, I know this. And then when it was real, I didn't know anything.

David Lowry: 2:58

Yes.

Bobby Kern: 2:59

And I was actually supposed to give that same lecture in the 4 p. m. section of that class that day. That class got canceled.

David Lowry: 3:07

I can only imagine. Tell me, what was going through both of your minds when this news was delivered.

Bobby Kern: 3:14

It was shock. Even taking the high risk tests that my wife took we never thought anything was going to come of that. We just thought, okay, this is just routine because of our age.

David Lowry: 3:26

That's what they do.

Bobby Kern: 3:27

Yeah, just what they do. And so it was never on our radar there was going to be anything. We both handled it in very different ways though.

David Lowry: 3:36

Do you mind talking about that?

Bobby Kern: 3:37

Yeah, absolutely. Because both those paths are important. My wife, Lisa, she dove headfirst into, Everything Down Syndrome. She started reading literature. She made connections with other parents and professionals, and she spent the next several months learning everything she could. I retreated into myself. You guys both know me.

That's not who I am. But I became very quiet, very reserved, and very angry. It wasn't supposed to happen to us.

Don Drew: 4:09

Yeah, and of course after you're walking out, nothing has actually changed. I mean, in the sense that she's still pregnant, you're going to have a boy, and it's a sudden change of awareness but you've still got months to go.

David Lowry: 4:21

I understand you were offered the opportunity to terminate the pregnancy, but you said no.

Bobby Kern: 4:27

We said no. And this was another thing. I don't think either of us ever thought that would be a question for us. That wouldn't be something that we would do. But I gotta tell you, when you are posed that question, it makes you stop. And we paused and it wasn't an immediate, no. There was a look in each other's eyes and like, what are we going to do? And I actually tell my classes this a lot when we talk about the realities of abortion and working with families. Having lived that it doesn't matter what you think, you know, until you're in a situation. It doesn't matter what you think you believe until you're in a situation. And there are times even now, and we'll probably get into some of the struggles, but there are times when Josiah is struggling with things now that even if for the briefest of moments that thought creeps into our heads. Did we make the right decision? Because it's hard to watch your child struggle with things physically, emotionally, socially, and know that you made the decision for them to be here to struggle with those things.

Don Drew: 5:31

And Bobby, you have other children.

Bobby Kern: 5:33

Yes. Yeah.

Don Drew: 5:34

Yeah, how did they relate with each other?

Bobby Kern: 5:36

Our daughter was three when Josiah was born. He hung the moon for her. And as they've grown up, that is reciprocal. She hung the moon for him. The coolest thing about that relationship is it has made our daughter who is about to finish middle school, she's gonna start high school next year, the fiercest advocate for not just people with Down Syndrome, she is the fiercest advocate for any marginalized population you can think of. She speaks her mind. She goes to bat for people. She has never met a person that she will not love whether she likes them or not. She's going to love them and fight hard for them. And that is such a cool thing to see your child do.

David Lowry: 6:19

Now that this is a reality in your life, you've got the news, it's gonna happen, you've made the decision to go forward. Did you find peace or was it more of a journey for you?

Bobby Kern: 6:29

It was a journey for me. Definitely pre-birth, I had no peace. We also knew that Josiah had some holes in his lungs and some holes in his heart. The holes in his lungs closed. One of the holes in his heart closed, but we knew even before he was born, that he was going to have an open heart surgery and that happened at three months. So, there was even a period of time after he was here that I was still very, very angry. I'm still on this journey of trying to find peace with all of it-- with being the parent of a child with a disability, but also peace with this God that I thought I knew and understood and who I had been told all along was love. And yet, here's this little innocent child at three months old that has to have open heart surgery. And I struggled with reconciling those things, which surprised me as a person of faith, and as somebody who has dedicated my life working in ministry and pastoring young people, especially. I was surprised by my own feelings there.

Don Drew: 7:25

Bobby, when you found out that Josiah was on the way and that he would have Down Syndrome, what kinds of responses did you hear? What kind of challenges did they present?

Bobby Kern: 7:35

So, we got a lot of feedback from everybody it seemed like everybody had something to say. I've since labeled a lot of it unintentional ignorance. People weren't meaning to hurt us, but some of the things they said ended up being hurtful. One of the things when we finally announced that he was coming, that he had Down Syndrome we often heard, well, we'll just pray to God that he takes that away. And, I get the sentiment behind that, but that's really not how genetics works, right? We're trying to come to the reality that our child is going to have Down Syndrome and then having someone say, well, we'll just pray it away-- man, that was hard. After he got here, we quite often heard things like, he doesn't look like he has Down Syndrome. Are you sure? Maybe they got it wrong. Or maybe it won't be that bad of a case. So, people don't often know what to say and so they just say what comes to their mind. Those types of things actually can be really, really harmful. And the reality is, before Josiah came along, I was the exact same way. So, it's made me more cognizant of how I talk to people about anything that's going on in their lives. We don't always need somebody to fix our problem. We need somebody to come in and just love us in the midst of it.

David Lowry: 8:53

What are some agencies or organizations you would recommend people contact right away when they find out this information?

Bobby Kern: 9:01

The two national organizations that one should check out the National Down Syndrome Society, NDSS, and the National Down Syndrome Congress, NDSC. Most states have

a local Down Syndrome organization. Here in Oklahoma City it's Down Syndrome Association of Central Oklahoma. There's also a Down Syndrome association in Tulsa. Most big metro areas have something like that. Both of those have very unique targets. One is more about science and research and family, and the other is more about advocacy. But both of them are very important orgs for families.

Don Drew: 9:36

How old is Josiah now?

Bobby Kern: 9:38

Josiah is 10. He's about to turn 11.

Don Drew: 9:40

Okay. So you've had some serious experience navigating the healthcare system and advocating for education and things of that nature. Can you talk about that a little?

Bobby Kern: 9:48

So, healthcare is what it is in our society. People that are born with conditions that are going to require more care it's a roll of the dice whether you're going to get what you need or not. Now, we have been really blessed. The state of Oklahoma had a program for young children called Sooner Care. We've been provided with a supplemental insurance, an SSI insurance and Sooner Care has helped. It's really kept us from going bankrupt. The heart surgery would have done us in. It basically comes in and pays the difference after primary insurance. Heart surgery is just the tip of the iceberg with our kids as far as medical problems that they might have. The real battles are in the educational system. We are not a system that is built for disability. And it's a struggle. We fight a lot for inclusion. We want Josiah to be in the mainstream classes. We want him to be around the general ed population as much as possible. There's so much good that comes from being surrounded by your peers. And the scientist in me read the research and inclusion, Always is correlated with positive outcomes for not just the child with the disability, but for every other child in the class as well. And so we want him to be a part of that. We want him to grow socially, emotionally, to be with his peers, even if he has some intellectual delays.

David Lowry: 11:17

Bobby is a minister in addition to his work as a college professor in family studies and there are some difficulties in religion in the sense that there are no special needs classes in most churches. It exceeds what they have to offer. That was probably revelatory to you as well.

Bobby Kern: 11:36

It really was, and it actually has led to some pretty cool, not just conversations, but some opportunities for me professionally. I've been able to go into churches and talk to them about disability, church's response to disability, ask big questions, walk around church buildings, and point out all the things that might be stumbling blocks for people with disabilities. And that's been really cool. And the times that I've gotten to do that, it's been well received.

Don Drew: 12:01

One of your jobs has been to advocate for our public policy to care better for children with disabilities and so forth.

Bobby Kern: 12:08

We, do a lot of that. We spend a lot of time with our representatives, especially on the state and the local levels. Those are where things get done. Our reps know us by name. The school board knows us by name. I actually ran for our city school board a few years ago on inclusive education. We advocate almost daily for changes.

David Lowry: 12:27

Bobby, can you tell us some stories or moments that gave you hope during the difficult times and maybe gave you the strength to persevere?

Bobby Kern: 12:36

I'll start with a story that is not about Josiah. One of the first things my wife did when she was processing everything was she connected with the Down Syndrome Association here in Oklahoma City. She was able to make connections there. The association also reached out to me and there were two dads in particular, whose kids are just a year and a few months older than Josiah. They reached out to me and it was life changing. It was what I needed. They let me see, them interacting with their sons. They talked to me about their experience and how it was going to be okay. They were there for us during the open heart surgery and they've really become dear, dear friends. They brought me along because Other dads brought them along. And now 11 years into this journey, I'm getting to do that. I do it all the time. I get to help bring new dads along. It's a beautiful thing. Josiah stories are numerous. I think probably my favorite, I was a baseball player growing up. Played at almost every level. It was my passion. My dad played ball with me, taught me how to throw and catch. I always had this dream in mind of being able to do that with my son. When Josiah came along, literally, one of my first thoughts was, well, there goes baseball. Guess what Josiah's favorite sport is? Baseball! We play catch all the time. I've got to coach him on his teams. We've had fully inclusive teams where I coached one team. We had four kids with Down Syndrome, one kid with palsy and six or seven typically developing kids. They all got along great. You'd had never known anybody had a disability. They were learning the game of baseball and it was a blast to see them out there interacting and having fun-- that's what it's about.

David Lowry: 14:19

And they to learn the lessons that sports has to offer.

Don Drew: 14:23

Okay. So, not everybody understands Down Syndrome. What are some of the stigmas and misconceptions you've run across?

Bobby Kern: 14:30

The biggest one that we always hear, Oh, those kids are always so happy. And that is not true. People with Down Syndrome, they have the same emotional makeup as all of us. They feel the same emotions. They engage the same behaviors. They're learning

emotion regulation, just like all of us. And we need people to understand that Josiah is cranky sometimes. He gets upset. He's angry. He feels everything that we feel. We do a disservice when we label any group as one particular emotion, even if that emotion is happiness, because that didn't allow him to be anything else.

David Lowry: 15:04

I never thought about that. We see all the smiling faces and it's good that we portray disability in its most positive light, but it sometimes keeps us from understanding the seriousness of a disability and the needs that go with it.

Bobby Kern: 15:18

One of the things that goes along with this portrayal of happiness is this idea they can't do anything else. They have this childlike happiness and so we don't allow them to grow up. Then we assume they can't do things like be in relationship or have a drink, right? Or talk intellectually about things. Adults with Down Syndrome will tell you, stop assuming things about me. I'm just like you.

Don Drew: 15:45

A lot of our listeners have different kinds of challenges, not necessarily Down Syndromes, but children with various kinds of disabilities. What is some way in which having a child with Down Syndrome has changed your perspective on life and what's truly important?

Bobby Kern: 16:00

I am far more in tune with relationships. I just want people to know they are loved. And It's directly because of Josiah, but it really has more to do with what I talked about a little bit ago with my daughter and watching her develop through all of this. She's my hero. I want to be just like her. I don't have time for marginalizing anyone for anything anymore. I don't have time for negativity and excuses in relationships. I want to love people. I want them to know they are loved. And man, what a better world it would be if we all just stopped and said, Hey, how are we alike? Stop focusing on differences. A few years ago, the tagline for the National Down Syndrome Society, was More alike than different. And that was exactly the point.

Don Drew: 16:48

That's a great point, Bobby. And I know Josiah is involved in a lot of different things. You mentioned baseball, but what are some of the other things that he does? I hear you talking about him all the time.

Bobby Kern: 16:57

Man, he's involved in so much. He is my athlete. He loves baseball. He plays basketball. He's in special Olympics. He swims for special Olympics. He runs track, does a softball throw. He does tennis, loves tennis. He's been in musicals, fully inclusive musicals. He loves being on stage. And then my favorite thing that he has done is with me. I dabble in comedy in both improv and standup, and we've created an entire set of dad jokes. And Josiah will be on stage with me and while I'm delivering these corny dad jokes, he is my rimshot guy and he will play the snare drum and hit the rimshot and

everybody laughs. It doesn't matter how dumb the joke is, and he soaks it all up because he knows they're cheering for him. They don't even care that I'm on stage.

David Lowry: 17:45

How has Josiah made you a better person, partner, parent, all of those things?

Bobby Kern: 17:52

He definitely has challenged me to challenge my own assumptions about anyone, right? I try not to walk into any room assuming anything about anyone anymore because Joe has taught me that everyone has something to offer and it's always beautiful. It's always valuable. And that's how I want to approach people. I don't see that extra chromosome. I don't see Down Syndrome. When I look at him, I see my kid and he's got my personality. He looks like me. He is definitely a chip off the old block. That's all I see. I just see Josiah. And that's what I want others to see. And if I want others to see Josiah when they look at him, then I need to see who they are when I look at them.

Don Drew: 18:37

There is something I've been meaning to ask you for quite some time, Bobby. He has a nickname. What is that about?

Bobby Kern: 18:43

Yeah. His nickname is Buggy Joe. So, when we were pregnant with him, we did not have a name yet. We were trying to figure out what we were going to name him. And our daughter who I mentioned was three said, let's call him Buggy. And so we started calling him Buggy. Yeah. I don't know why, but we started calling him Buggy. And then we settled on the name Josiah Matthew. Josiah, actually means Jehovah heals. And what we thought we were naming him was about him. What we realized was that Jehovah has used Josiah to heal us, which is really cool.

David Lowry: 19:23

That's powerful.

Bobby Kern: 19:24

And Matthew is named after my best friend, so there's a connection there. But we put them together and Buggy Joe was born and that's what we've been ever since.

Don Drew: 19:33

What recommendations would you give someone faced with a similar situation that they have a child that's going to be born with Down Syndrome? What would you say to them?

Bobby Kern: 19:43

The first thing I tell them congratulations! Congratulations, because not many people have said that to them. And we remember that. Usually it's, Oh, I'm sorry. No, we're not sorry. Congratulations! You're going to have an amazing, beautiful child. I might introduce them to Josiah. I might share with them some of my own stories, but I'm not going to force things upon them. I'm going to remember what it was like trying to process all of that information. And allowing them to process it at their speed in their

way, it's going to be really important. But knowing that, I'm going to be there. Lisa is going to be there and we're going to show you how great this life can be when you're ready and not abandoning them, but letting them do that at their own pace. And then when they are ready to hear and see it, we're going to show them what it is. It's great. We have the same ups and downs with Joe that we have with our daughter. We have the same parenting struggle. Sometimes we do it really well and sometimes we have no idea what we're doing. It's showing them the only difference is that this child has one extra chromosome.

David Lowry: 20:41

Along the way, you probably heard some great advice or a saying that stuck with you. Do you remember any of them?

Bobby Kern: 20:48

Yep. I had right off the top of my head. It's become our family motto It's Dream big! Dream big. We were told early on, do not have any less dreams for your son than you would for any of your other children. You dream big for them. And that's what we do. And we have adopted that not just for Josiah, but for all of us because we're all still growing and developing and changing. And we have big dreams for all of us as individuals. We have big dreams for our family. And we're not gonna shirk those off. We're going to chase those dreams.

Don Drew: 21:22

Bobby, what advice would you give to someone who is struggling to find hope and inner peace in the midst of a difficult life situation of any kind, regardless of the specific circumstances?

Bobby Kern: 21:31

The best advice I would give is advice that I received, and that's just pause. Find rest. Rest might be physical rest, but it also might just be silencing the outside for a little bit. I'm a person of faith. Connect with that thing you can't explain and maybe never will be able to, but that brings you peace inside in whatever way you need to do that. And then, just do life. Raising our child got exponentially easier when I just started raising our child.

Don Drew: 22:09

Bobby, you've been an inspiration to me for years, and I know you're an inspiration to thousands of others, so thank you.

David Lowry: 22:15

Bobby, I want to let others reach out to you who might be struggling with a special needs child or going through some of the same things you struggled with years ago. Could you tell us how we might get a hold of you?

Bobby Kern: 22:28

The best way to reach me is at bobbykern24, bobbykern24 at gmail. com. I am happy to talk with anybody. I do a whole lot of that. We are always willing to sit down with families and share our story and we want people to meet Josiah. So, that's the best way.

David Lowry: 22:48

As our conversation with Dr. Bobby Kern comes to an end, it's clear that his story is one of resilience and compassion and also the power of finding peace in the midst of life's challenges. Bobby, thank you for being here and we look forward to having you again sometime.

Bobby Kern: 23:04

Oh, I'd love it. Thanks for having me.