

An interview with Karla Akins, Author of *A Pair of Miracles*



According to the Centers for Disease Control and Prevention, an estimated one in 68 children has been identified with an autism spectrum disorder (ASD). Although a growing number of parents face similar circumstances, many still feel isolated and alone. In *A Pair of Miracles: A Story of Autism, Faith, and Determined Parenting* (Kregel Publications), author Karla Akins, the mother of twin sons with autism, offers encouragement and reassurance.

Q: Tell us a little bit about your family. How many children do you have, and how did your family come together?

I have one step-daughter, two biological sons and two adopted sons. We had struggled with infertility and came to foster parenting because of our desire to have another child.

Prior to adopting the twins, we had two foster children who were adopted by other families. It was after a foster baby we had from birth to almost 11 months old and was given to an adoptive family (the agency we were with would not allow foster parents who already had children to adopt) that God gave us the opportunity to be foster parents to the twins.

Our social worker (who knew we wanted to adopt) called, and we had about 30 minutes to decide whether or not to say yes. I knew I'd never be able to let them go, so I sensed this decision was an adoptive decision, not just a foster-parenting decision.

The twins were preemies, and Isaiah came home from the Neonatal Intensive Care Unit first. A month later Isaac came home, and the adventure began!

Q: A few months after you brought your adopted your twin sons home from the hospital, you learned they were born with Fetal Alcohol Disorder. How did they behave differently from other children, and what clued you into the fact something else might be wrong?

The twins screamed constantly and were very, very difficult to calm. They had an amazing stamina when it came to screaming and could scream for hours. They would start screaming even before they opened their eyes to wake up.

Doctors chalked this all up to the twins being premature. Because they were premature and born to a "low-functioning" mother, they didn't really give us any other explanation. It was a given in their mind that due to their prematurity they would have unusual behaviors. At three months they were diagnosed with microcephaly (their skulls too small for their brains), and it was assumed, because of their facial features and small head circumference, it was due to fetal alcohol disorder. Fetal Alcohol Syndrome Disorder (FASD) is difficult to diagnose (at least it was back then) because you need to have the mother's admission that she drank while pregnant. We didn't have that admission, but the twins are textbook cases of the syndrome.

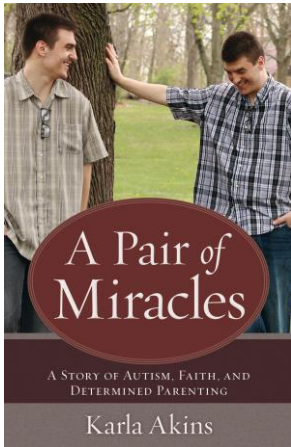
When they were diagnosed with microcephaly, I was determined they wouldn't keep that diagnosis. I laid my hands on their heads every single time I touched them and prayed their heads would grow. God answered that prayer. They have regular-sized head circumference! Truly a miracle. If they didn't, their cognitive functioning would be much worse.

Q: How old were the boys when they were diagnosed with autism? How much did you know about autism before their diagnosis?

The twins were four years old when they were diagnosed, but I knew something was wrong years before the official diagnosis. Not only were they a textbook case of FASD, but they are of autism as well. It's important to remember that autism can have co-morbid diagnoses. In other words, having autism doesn't mean you can't have other diagnoses as well. Did the FASD cause the autism? We have no way of knowing.

When the boys received their autism diagnosis, the only thing I knew about autism was from the movie *Rain Man*, which means I knew nothing! Plus, autism is different in every individual.

In 1997-98, the only thing I had was a rickety old IBM computer someone had given me. It barely worked and was one of those with the green screen, but I used it to hook up to AOL. (I can still hear that dial-up sound in my ears!) Once online, I connected with an amazing crew of mamas and grandmas who also had children with autism. It was those women who led me to resources. I have to tell you, we were on the cutting edge of research in those days, but as far as early intervention was concerned, it was very difficult to get anyone to listen to us regarding what our children needed to have to succeed. It was very, very hard to get people's attention. If it weren't for those women, I don't know how I'd have survived those early years. They were a lifeline.



Q: Who will benefit from reading your new book, *A Pair of Miracles: A Story of Autism, Faith, and Determined Parenting*?

I hope families and caregivers will be encouraged by reading about our journey and might gain a few ideas on how to work with their child. I also hope they will feel like they're not alone in the struggle. I know I like to read books that validate what I'm feeling. It's always good to know you're not the only one in the trenches, fighting the good fight of day-to-day survival with autism.

I've included a generous section on how to work with your child. These include ideas that worked for us but also some evidence-based interventions proven to work for a lot of children with autism. Since I'm also a special-education teacher, I hope the book will help educators understand what families deal with. I've sat on both sides of the IEP table. I know the stress of advocating for what's in the best interest of my child, but I also know how it feels to be an educator. Educators and parents need to work as a team, and the book gives great tips on how to do so.

Q: What was the doctors' prognosis of how the boys would be able to function as they grew and matured? How did you work through the grief that followed the news?

The working title of this book was *Pie in the Sky*. I was told by a psychologist my hopes and dreams for them to function independently was "pie in the sky thinking" and I "better get over that right now." I never went back to her. The boys have done much, much more than anyone thought possible.

For instance, that particular doctor told me they'd never read, be able to live independently or speak. Other doctors simply didn't know and told me I would have to wait and see. Only one doctor I worked with was sympathetic to me, and it wasn't anything he said, but it was how he treated me with such kindness and respect when we'd see him. I wish there were more pediatricians like that today. He never gave an opinion about the future. He just helped me get through each medical crisis and was very encouraging to me. He made me feel like I was competent.

Today the twins walk. They talk and understand everything that's said to them. Their speech and language is a little difficult to understand at times, but they function well enough to send text messages and talk on the phone.

I worked through my grief about their diagnosis in stages. In some ways, I already knew something was wrong. Developmental pediatricians were tracking their physical development, and we could already see some things about their development weren't right, such as the size of their heads. I also knew the way they reacted to sensory input was way off, and they weren't meeting their developmental milestones on time, such as sitting up, walking and talking. Still, even though I knew something was wrong, I went through all the normal stages of grief — from anger to acceptance. I still do go through some of the stages. All parents with special needs kids deal with grief on a day-to-day basis. It cycles through us at various times depending on what we're dealing with. Mostly, though, I'm so proud of my guys. They've worked hard to get where they are today.

Q: When the boys were young, in a meeting with your pastor, he asked, “Do you think you missed the will of God when you adopted them?” Even doctors made hurtful comments to you about your boys. How did you respond?

Well, I'd like to say the conversation doesn't still bother me, but it does. I do realize some people just don't "get" adoption and disability issues. I've forgiven the pastor and those doctors, but just thinking about those conversations makes me shake my head with incredulity. Some people don't have filters. They just say whatever they're thinking.

I was furious, of course, when those conversations took place. I never responded negatively or rudely to them at the time, but I did stew on what they said. I'm the type of person who when you tell me I can't do something or can't make something better, it fuels me to prove you wrong. I used those conversations to motivate me rather than discourage me.

Q: You talk about bargaining with God and even encourage readers to “wrestle with God” in difficult times. What were some of the questions you had for God in the early years of raising Isaac and Isaiah?

I would actually pray for forgiveness from God for wanting to adopt because I sometimes worried about what it was doing to our family. It definitely took away the tranquility in the house. I am a huge peace-lover and maker. I crave quiet spaces. I also asked my husband to forgive me for pushing for adoption, but he never once wavered or questioned our decision. That helped me a lot in the twins' younger years when they were so, so hard to care for.

I still have a lot of questions for God where disabilities and pain in the world are concerned. However, I do know the devil hates humans and wants them to suffer because we are created in God's image. Still, God's ways are not our ways, and I truly believe He will use our struggles for His purpose and glory if we let Him.

Q: What have your boys taught you about God, and how has your faith grown by being their mom?

The boys have taught me more about everything in life and especially about God. I've never seen greater faith than theirs. I've never seen joy such as theirs. The twins have amazing faith. To me, they're spiritual giants. Their faith in God inspires me every single day. Their spirits aren't at all disabled. Their spirits are as healthy as yours and mine and probably even more so because of their childlike faith.

They are very tender-hearted toward the Lord, and they know to turn to Him for help. Just a few days ago we had a situation that made Isaac anxious. He asked if we could all pray, so we stood in a circle and prayed. He sobbed like a baby, crying out to the Lord for help. That is faith. Without faith it's impossible to please God (Hebrews 11). Their faith amazes me. I am eager to interact with them in heaven when they are completely healed and to talk to Jesus about them and how their prayers affected heaven. They are true prayer warriors. When I need prayer, I ask them to pray because of their great faith.

They've taught me what's important in life. I'm not as materialistic as I might have been otherwise because autism doesn't allow you to have breakables. Doors get kicked in. Walls get holes in them. Furniture gets mauled. They've taught me not to sweat the small stuff. My tolerance for imperfection is extremely broad because of them. Societal constraints don't worry me. Our yard might not be the prettiest in the neighborhood because we're so busy supervising the twins, but the love in our house is immeasurable. It's far from perfect, trust me, but when I focus on the blessing these boys are to others (they love serving people), I'm deeply humbled. I wish I could be as sweet as they are.

My faith has grown as their mom because what the world said could never happen, God made happen. When doctors told me they were microcephalic, I refused to accept it. As I mentioned earlier, I constantly laid my hands on their heads and told them to grow. They have normal-sized heads now. Doctors said they'd not walk, but they walk. Doctors said they wouldn't read or do much independently, and with God's grace we've proved them wrong.

Q: You include sections with scripture to meditate on. What verses have meant the most to you throughout the years?

Psalms 139 is my favorite scripture passage because it talks so much about how God knew us before we were born and how He is always with us.

I've also leaned a lot on the book of Job for inspiration, especially Job's attitude in Job 13:15 (KJV): "Though he slay me, yet will I trust in him: but I will maintain mine own ways before him."

Job is saying, "I trust God no matter what, but I'm still going to be bold in going to Him."

There are many things that happen I don't understand, but this verse keeps me praising instead of complaining. It also gives me permission, in a way, to wrestle with God about the hard stuff that goes on in my life. It also helps me realize I can trust God, even when things don't make sense. He's in control.

Q: What misconceptions do most people have about autism? What would you most like your readers to understand about autism?

I wish more people would understand autism is different in every person. It's a spectrum disorder, which means there's a wide spectrum people fall on. I have friends with children who have a severe form. Their children are grown now and still can't toilet themselves. I have friends with children who have children who are considered high-functioning because they have high IQs, but the child can't shower independently without guidance. It's a neurological disorder, not a behavioral or psychological problem, and it manifests in a myriad of ways. When you've seen one child with autism, you've seen one child with autism. It will look different in another child.

Q: For parents who are walking the road of raising children with autism, what advice do you offer for becoming the best advocates for them when it comes to medical care?

Trust your God-given instincts, and don't second-guess yourself. God gave those children to you, and He will equip you to do what is right if you seek Him for answers and wisdom.

Put everything in writing when you have a concern that isn't being answered. Do your research to make sure any treatments you desire for your child are based on evidence and not trends.

Q: What are some of the other areas you discuss in the book for living life with autistic family members?

I really want parents to take their children out in public and de-sensitize their kids with autism to uncomfortable situations. Yes, it's inconvenient, but you do your children no favors by hiding them away at home. Society needs to see them, and the child with autism needs to be exposed to the sights and sounds of the world so they can learn to cope.

I talk about how difficult mealtimes were. They were a nightmare when the twins were small. Food was thrown everywhere, and a lot of screaming went on. Looking back, now I can see the screaming was from anxiety, but I didn't realize it then. We learned the twins ate better if they ate in the dining room while we ate in the kitchen. We all had to learn not to take it personally. It was just what it was. At that time, our kitchen had a cut out in the wall to the dining room. We'd put two vinyl table cloths on the floor under their high chairs and let them go at it. It was the only way we could eat and have a conversation. Every meal ended up with them painting themselves head to toe with food. They couldn't eat solids because they had poor motor control, so I pureed everything for years.

I also discuss the need for a network of support because of how stressful it is to raise a child with autism. I learned I couldn't care for the boys without help, and I needed to admit it.

Q: How were your other children impacted by their brothers' autism? What recommendations do you have for parents to make sure their other children don't feel overlooked?

If I had my kids to raise all over again, I'd have been more deliberate in scheduling one-on-one time with each of my children. I think we were too busy. I try not to second-guess myself, but it's hard not to. What parents absolutely must not do is depend on their other children as caregivers. Yes, definitely, they can help out because that's what families do. However, every child needs to feel they are a child and sibling, not a parent.

Q: Tell us about Isaac and Isaiah today. In what ways are they able to function independently in ways the doctors never expected? In what areas do they still need help?

They do so many things on their own! They have a golf cart they use for transportation to their part-time jobs and other places in town. Fortunately, we live in a community that allows it. They use their smartphones and iPads to communicate and read things. They attend church and help with various duties there. Isaac helps with the sound system, and Isaiah loves helping in children's church. They are amazing helpers. They love helping people.

The twins will probably always need to live with someone who can protect them from being taken advantage of. They have a difficult time counting money, so it's easy to cheat them. They can also be talked into doing things, as they are quite naïve and gullible. They have dual-diagnoses of fetal alcohol disorder and intellectual disabilities, so that makes dealing with them a bit more involved. They still need to have reminders for daily self-care and function at about the level of an 8- to 11-year-old. They still need to be prompted to do their daily chores (don't we all?) and so forth.

Q: Can you share some of the basics teachers at church and ministry volunteers should know when working with a child who is autistic or has disabilities? What tools are offered in your book?

My book has a great appendix that answers questions about working with people with autism. I give a lot of great tips on how to respond to different behaviors and how to motivate kids with autism.

Remember all children are unique, no matter what their ability or diagnosis. Also remember a diagnosis is not who they are. They are children and people first. They just happen to have a label.

Churches can embrace families living with disabilities by providing one-on-one aides in the child's classes so the parent can attend their own classes. This also allows the child with disabilities to attend church with children their own age too.

I offer training to the teachers and those working in the children's department. I love giving training seminars. People can contact me through my website. I also do one-on-one online consultations as well. Folks can sign up on my scheduling page.

Learn more about *A Pair of Miracles* at www.KarlaAkins.com. Akins is also on [Facebook](#) ([KarlaKAkins](#)) and [Twitter](#) ([@KarlaAkins](#)).