

Julianna's Journey: Grief and Hope in Community

By Eric Saylor

Series: Presence With: One Another

What a blessing to worship together. To seek God's face. To rest in His goodness.

Thank you for allowing me to be with you this morning. Of course, that was Jake's decision. Thank you, Jake.

He said he would be checking in later. He is ministering to an essential group of young people this week and today. Just so you know, my name is Eric. I get to be Jake's pastor.

[Congregation responds]

Yeah. I used to be his roommate.

Back in November, I began a new role in our region as the pastor of the pastors. And when I began that job, I didn't have a place to live. And so Jake graciously said, come crash on my floor. Better than sleeping in my car. And so from November until March, I would spend the week with him. And we've been friends for a long time.

Today I want to share a bit of the story of my family with you. Not the whole story. This is a part of the story that is very formative to who I am as a child of God and who I am as a minister of the gospel. And Jake actually is a part of this story, and let me share a bit why.

I have three kids, and one of them—I'm going to share the story with you today of her. Her name is Julianna, and Julianna loved Jake. And I'll get into a little bit more of that story in a bit. But when I arrived at my previous church—I was there for eleven years—when I arrived there, Jake was my first student pastor. Every year I would get a student pastor from Walla Walla University, and he was my first student pastor. And Julianna loved Jake with all her heart. And we landed there in 2014, and Julianna was six at the time. And today is her story.

By way of introduction, though, I want to jump into Scripture for a moment—into a story that kind of parallels our story. The story from Mark chapter 5.

Now on the screen—if you'll jump to the next screen, you'll see Mark chapter 4. I messed up. It's supposed to be Mark chapter 5. Please forgive me. Mark chapter 5—you'll find the story there of a man named Jairus. You probably know the story. Jairus had a little girl, and he was a leader of a synagogue. He might be considered what we would call today a minister, a pastor, a leader of a local spiritual community. And Scripture tells us:

Then one of the leaders of the synagogue named Jairus came, and when he saw Jesus, fell at His feet and pleaded with Him repeatedly, "My little daughter is at the point of death. Come and lay Your hands on her so she may be made well and live."

Daddy's here. Mama's here. If you had a child who was at the point of death, would you too go to Jesus' feet and repeatedly say, "Lord, my little girl is sick. Please come lay hands on her so that she may be made well and live." Can you hear the daddy's heart in that?

[Congregation responds]

Yeah, I can.

Next screen, please.

So He went with him.

He went with him. When we invite Jesus into our life, into our situation, into our experience, Jesus promises to enter in. No question. No question. When you say yes to Jesus, when you go to Jesus, or when He comes to you and you say yes to Him, He enters into your life, into your experience, into your story, and you have guaranteed proof that He's there because He says that He will do it. No question.

But there was a bit of a problem, because Scripture tells us in Mark chapter 5 that Jesus was delayed. Jesus was delayed. Sometimes it feels like Jesus is delayed in our lives. You ever experience that? Maybe there's a situation with family or finances or relationships or whatever the issue is, and you invite Jesus into that space. You can trust that He enters into that. But sometimes things don't go exactly the way you had imagined them. Even though He's there, it feels like Jesus is delayed.

Let's go to the next picture, please.

Julianna was born in 2008. I was at seminary at the time, experiencing growth in my theological and organizational leadership skills. But more important than all of that—while we were at seminary, we landed with one kid, Joshua, who's now almost twenty-two.

[Congregation responds]

Yeah, they grew up quick. And we left seminary with three kids. Julianna was our second. We arrived at seminary pregnant. Yes, I had a part in it, but I wasn't pregnant. She was born six weeks premature. Six weeks premature. Spent some time in the NICU, experienced all that stuff. And while I was trying to go to classes and Stacy was recovering from a C-section, we were navigating having a little tiny baby who was having trouble breathing and all the rest. And so she spent twelve days in the NICU, and we got her through that. And she was strong and she was healthy. Beautiful little girl.

Please go to the next slide.

And as she grew, we moved back. And of course, Jillian, our youngest, was born toward the end of our time at seminary. And we moved back here toward the Northwest, because Northwest is best. We landed in Pendleton. If you've ever been to Pendleton, I was pastoring the Pendleton and Pilot Rock churches, and she was a beautiful little child. She grew and she developed. She became kind of a young lady. She began to be a young lady.

We accepted the call to join the team at Eastgate. Next slide, please. And this is Julianna at eight years old with her puppy, Ellie. Eight years old. We integrated into that Eastgate church. And Eastgate had been through kind of a rocky time. And they were looking forward to how they might be able to make a difference in the community and share the gospel of Jesus with people who needed Him. And we joined the team, and we had spent about two years there building the direction forward and visioning for where we were going—kind of like where you guys are going right now. What is God doing in us, through us, and in the community? And how can we join in with that? And we were excited about what God was doing. And here my family was coming along with me in this journey. And Julianna is eight years old.

And one Sabbath, we spent the day at a friend's house for Sabbath afternoon. Kids were playing, ate some wonderful lunch. And on the way home, Stacy noticed something. When we got home from that family visit, that fun afternoon, Stacy noticed something with Julianna's eye. When she would look to the left—trying to remember the way—when she looked to the left, her eye would go all the way over to the left. But when she looked to the right, it wouldn't go past midline on her right eye. We thought, this is weird.

I appreciate my wife, because ladies are intuitive, right? And they notice things that we men sometimes miss. Have you noticed that? She said, there's something wrong here. So we looked at Julianna and we said, "Julianna, look this way, look that way," and her eye wouldn't go right past midline. And so we called family members who are medical people and nurses, doctors, things like that. And we're like, what's going on? What do you think? And they said, go to the hospital. This is neurological.

So we jumped in the car, eleven o'clock at night, ran to the emergency department there in Walla Walla. They got us in within, I don't know, a half hour probably into the room and did all the neuro checks and all the stuff. And after a while they said, you know, you really need to go somewhere where you can get an MRI. But here in Walla Walla, we don't have a child's MRI. We don't have a way to get her effectively scanned here in Walla Walla because we don't have the right equipment. And so you need to go to Spokane.

So we jumped in the car and we drove—Stacy, myself, and Julianna. The other two kids stayed with Grandma. And we drove to Sacred Heart. Got there at 1 a.m. Waited in the waiting room for a little bit. Once again, you know ERs. Got the MRI, took forty-five minutes, and that little girl laid there for forty-five minutes with the MRI banging around her head, right?

Let's look at the next screen.

And as they did so, they found a mass in her brain stem. At first we didn't know what to think. Obviously when you know there's something wrong with your kid, but you're not sure what you're looking at—all the possibilities you're trying to think through. What could this be? What are the possibilities? Is it serious? Is it something treatable? What's going on?

And after some troubleshooting and a biopsy, we realized that it was cancer. It was found in the pons. The pons is a part of the brain stem, and it's kind of the bottleneck that everything goes through from the brain to the body. Everything's got to go through there. And if you've got pressure building up in there, if you have a tumor in there, then it's going to affect everything communicating from your brain to your body, including her face, everything. And what it ended up being was something called diffuse intrinsic pontine glioma. DIPG. Inoperable. No effective treatment. Obviously no cure if there's no effective treatment. The problem is that all the good cells and the bad cells are all mixed up together. You can't separate them out. And because of the blood-brain barrier, you really can't have effective treatment with chemotherapy with our typical way we do things, because it's hard to get stuff across that barrier at levels that are effective.

And as we got into this journey, as we began this journey as followers of Jesus, the first thing we started doing is what? We said—absolutely. I mean, we were praying as a family prior to this, but man, we really started seeking the Lord, right? And here in Spokane at Sacred Heart, one of the first things we did is we invited in a group of local pastors who were my colleagues and said, guys, we want to anoint Julianna and ask the Lord's blessing on her. We ask that you would come and pray for her.

And so as she was sleeping one night, they came in—three, four of our friends came in—and we surrounded her bed. We put hands on her. Put oil representing, symbolizing the Holy Spirit on her

forehead. And we prayed for her. And I had two prayers. Two prayers. Number one: Lord, heal my girl, right? Obviously—heal my girl. I pray that You would—whatever is going on there—I pray that You would remove these evil cells from her body that she might be whole and healthy again. And the second prayer: Lord, whatever the path, I pray that You would hold her close and she would experience Your presence in her life. Right? Those were my two prayers.

Next slide, please.

The only treatment that is universally done for this type of cancer is radiation. And so we uprooted our whole family, and for a couple of months we lived here in Spokane—had a place up on the South Hill about eight minutes from Sacred Heart. And every day, except for weekends, except for Sabbath, Sunday—every day for thirty treatments, Julianna and I would get up at 6 a.m., drive the eight minutes down to Sacred Heart. She would lay down on that table, her face and head strapped down to this table while radiation is beamed into her brain. And this is her journey. This is her experience.

As all of this was going on back home in Walla Walla, we had a church that was praying for us. All the churches that I've served have been a blessing in my life. We have lifelong friends from each of them. But the church I was pastoring then—I think God brought us there in part because He knew the tragedy and the stress and the problems that were going to hit our family. And He established us in that community knowing that we would need them. We weren't there for them so much at that moment as they were there for us.

And as we went through this journey of cancer, they loved us so well. They carried us through this with their prayers. They respected our space. But they stepped in when we needed it with help and encouragement and support and guidance and love. And I'm so thankful to be a part of a church family that knows how to love well.

And my question today is, how can all of us as followers of Jesus be that to each other? How can we love well when life hits us? Because life hits us all. When we each go through our Job experience. Because if you haven't been through a Job experience, you will. In this world, you will have trouble, right? But take heart—Jesus says, I have overcome the world. And in part, I think, part of the way He overcomes the world in the midst of this brokenness is He has placed His people in this world. He has placed us in this world to be a little glimmer of hope and help and courage for those who are going through hard times. And we experienced that as we were walking through this journey with our precious daughter Julianna, because our church chose to love us well. They cared for us. They encouraged us. They respected us. And they lifted us up. What a blessing to experience what church can be when it's full of the Holy Spirit.

And that's my message to you today—at least at this moment—is how can you, how can I, as a part of the church, be intentional in loving well and caring for those who are hurting, who are going through messy stuff? How can we do that?

After radiation finished—over those thirty days of radiation—our main doctor who was overseeing her care was actually at Seattle Children's Hospital over in Seattle. And so one day we were over there doing a checkup with the doctor. And we were walking down the hall into a lobby. And on the lobby wall—if we can see the next picture, please—on the lobby wall was this display. And it said, "If my heart could speak, it would say." And then there's all these bubbles. You can see the word bubbles like in a cartoon kind of situation. And people were writing various things on those—all supportive, encouraging, or maybe even some of them were fear-filled, like, man, I'm scared of what I'm going through. All these different things were written in there.

And I saw Julianna walk over there, and I didn't prompt her to do this. She walked over and she picked up a pen. Next slide, please. And she began to write in the bubble. I was standing back

watching her thinking, what is she going to write? I don't know what she's going to write. Let's see. Let's see what comes out of her little heart, out of her mind. What would her heart say if it could speak? Next slide, please.

Jesus loves you.

When Julianna was first diagnosed here in Spokane, we were sitting on the children's cancer wing there, the cancer wing in the hospital. And as she was kind of absorbing the news that she had this thing that was cancer, and she was trying to figure out exactly how she should relate to this. And as she was absorbing the news—because we were up front with her—when she asked, "Am I going to die from this?" she asked us that question as an eight-year-old. We said, most kids do die from this. And as she absorbed that news, and we told her, the whole world is praying for you—because we were getting messages from people, followers of Jesus from across the world, saying, we're praying for you, Julianna, including our church family at Eastgate—she, in her mind, immediately started looking around her at all the other cancer kids on the floor there. And she said to Stacy, "Do they have a praying family too?" And she started calling them her cancer kids. And she would pray for her kids on the cancer ward here in Spokane.

And so you can see her heart, right? This girl loved Jesus, and she wanted other people to know that Jesus loved them too.

As we went through those thirty rounds of radiation, then went on to other experimental treatments—we were trying things that others had never thought of or that were cutting edge. And we did things that tried to put chemotherapy directly into the tumor through blood supply and through special catheters in London. We traveled as far as we could trying to find cutting-edge treatments to address this issue, because she's eight. She has a whole life ahead of her. Why wouldn't you try? But this was eleven years ago—ten, eleven years ago. Ten years ago. And even in the last ten years, though treatments have come a long way, there still is no cure. So obviously back then there wasn't one either. And after almost nine months, she got to the point where it was clear—nothing, nothing in this world was going to cure her.

Next slide, please.

Because of the steroids that she'd had for so long, her face had become puffy. But she was still, on the inside, that same girl. That same girl who prayed for her fellow cancer patients. The same girl who loved Jesus. The same girl who cared deeply for her little animals like her puppy, Ellie. She was the same girl.

But in August of 2017, Julianna closed her eyes. And they're still closed.

Back to Mark. Mark chapter 5, verse 35.

While He was still speaking, some people came from the synagogue leader's house to say, "Your daughter is dead. Why trouble the Teacher any further?"

Jairus said—there's nothing more we can do. Jesus is out of luck and so are you. Your daughter has closed her eyes for the last time. Don't bother Him anymore. Yeah, we've seen Him heal leprosy and blindness and muteness. But this is beyond Jesus. Don't bother Him anymore. Just come on home and have a good cry.

Next slide, please.

But overhearing what they said, Jesus said to the synagogue leader, "Do not be afraid. Only believe."

To Jesus, these situations are not hopeless. To Jesus, even death is not insurmountable. This is why Jesus calls death a sleep—because you expect to wake up from a sleep. Right? When I go to bed at night, I expect to wake up in the morning. And for Jesus, when someone passes away in sleep, He knows that that's not the end. But one day He's going to come back and He's going to wake up all those who, as Paul says, sleep in Jesus. Death is not too much for Jesus. Only believe.

One night as we were talking about cancer—Stacy, Julianna, and I were talking about our journey that we were going through. She ended up sleeping in bed right between us because she wanted to be with us. Life is hard when you're eight and going through cancer. And we were sitting in bed just talking about this journey we were going through and cancer and life and all the things that we were facing. We were very honest with her and she was very honest with us. She—obviously age-appropriate—she was very aware of what she was facing. And as we were talking about cancer, she said something that blew me away and has helped my faith incredibly. Next slide, please. She said:

I'm not afraid to die because I know Jesus has me.

I'm not afraid to die because I know Jesus has me. How many of us are able to say that today? If you have accepted Jesus as your Savior, if He is your friend, if you've said yes to Jesus, then you can say by faith the same thing. Even though you may not be facing cancer, you might not be facing a health crisis, you can still say, I can live with confidence knowing that I don't know the future, knowing that Jesus is with me and He has me no matter what comes. I don't have to live in fear because I know Jesus has me. And to hear your little girl who's facing terminal cancer say this was such a help to this daddy's heart.

Back at the beginning of her journey, as we surrounded her bed with a group of pastors and we prayed over her, anointing her with oil in the name of the Lord—I had two prayers in that moment. I already told you about them. Number one, that He would heal her. Yes. And number two, that He would hold her close. And Jesus has and will answer both of them. Jesus held her close and carried her through that whole experience—the whole nine-month experience of terminal cancer, ending in her closing her eyes in the sleep of death. He carried her through that whole thing. And that second prayer was answered—that He'd hold her close. And the first prayer, that she would be healed, will be answered. Will be answered. For the follower of Jesus, all illnesses, all sicknesses, whether terminal or not, will be healed when Jesus comes back. This is the promise for the believer. This is why Julianna could say, I'm not afraid to die—because I know Jesus has me.

Next slide.

So He—Jesus—took the child's father and mother and those who were with Him and went in where the child was. Taking her by the hand, He said to her, "Talitha cum," which means, "Little girl, get up." And immediately the girl stood up and began to walk about. She was about twelve years of age. And at this they were overcome with amazement.

Jesus had been delayed and she passed away. But Jesus was able to take that broken, sick, even dead little body and bring it back to life.

Now I believe with all my heart that one day soon, Jesus is going to break into our reality. Next picture, please. Jesus is going to break into our reality. And all those, including my daughter, Julianna, will be called by name and she will come back to life. We will wrap our arms around her once again. And I'm so thankful that she is secure in the arms of Jesus today—safe, ready for the resurrection. He

will recreate her. And this time there will not be a single cell of cancer in her body. She'll be whole and healthy once again.

And I know that each one of us today can point to people in our lives who have gone through journeys that might parallel Julianna. Maybe it's a parent, grandparent. Maybe it's a dear friend that you lost—a car accident or cancer or whatever. And you too can hang on to the hope that we have in Jesus—that death is not the end. Though they may sleep for now, Jesus is able to wake people up. And one day soon He's going to break into our reality and make everything right. Are you looking forward to that day? I am.

Would you pray with me?

Lord God, thank You for the promises that You've given us. Thank You for the hope that You've given us. Lord, I pray that our hearts and our minds and our lives would be so tied to You that we too can say, I'm not afraid to die or anything else because I know Jesus has me. May we be the kind of church that You've called us to be—where we walk with people through the brokenness of life, through the ups and the downs, the joys and the failures, the discouragements and the rejoicing. May we be the kind of church that honors You and draws all people to You. We love You and we're looking forward to seeing You. Amen.