

Season 6 | Episode 4

## Meet Neurosurgeon and Special Needs Father

### Ben Warf

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Crystal Keating:

This is the Joni and Friends Ministry Podcast and I'm your host Crystal Keating. Each week we're bringing you encouraging conversations about finding hope through hardship and practical ways that you can include people living with disability in your church and community. As you listen, visit [joniandfriends.org/podcast](https://joniandfriends.org/podcast) to access the resources we mention, or to send me a message with your thoughts.

Stephanie Daniels:

Hi friends. I'm Stephanie Daniels. Crystal and I are happy to be joining you today. I'm thrilled to introduce Dr. Ben Warf a pediatric neurosurgeon at Boston Children's Hospital and a professor at Harvard Medical School. He works with children all around the world who live with hydrocephalus, spina bifida, and other neurological disorders.

While working in Uganda, Dr. Warf developed a technique that revolutionized the treatment of intracranial diseases in very young children. In recognition of that breakthrough, he was named a MacArthur Foundation Fellow in 2012. Dr. Warf is also personally familiar with disability. His daughter, Sarah, lives with a visible disability that impacts how others treat her.

Dr. Warf sits on the Joni and Friends International Board of Directors and today he's sharing how his faith and his personal experience with disability inform his work as a doctor. Listen to Dr. Warf's heart. I hope you're blessed by his story.

Dr. Ben Warf:

I'm Ben Warf, I'm a pediatric neurosurgeon. I grew up in Eastern Kentucky in the Appalachian Mountains in a coal mining area. My father was a Baptist pastor. He was called to a church in Appalachia. At the time I was just a kid. I think I was in the fifth grade maybe. We lived in the western part of Kentucky. It was really a different culture. In the end, we loved it there and we loved the people. I consider that My home. That's really where I grew up, and I'm proud of that.

My wife Cindy and I got married pretty young, as we did in those days. We got married in college, and she actually encouraged me to even apply to Harvard. So that took us to Boston.

And in my high school and college years, I started to think that maybe God wanted to be some kind of missionary.

In medical school, I had that in the back of my mind, but I got very interested in research and the brain and went on to do neurosurgery. And my first job was at the University of Kentucky where I was on the faculty. But there was a drumbeat in the back of my head.

When I was about 13, I had publicly made a commitment to be a medical missionary. My father even said, “Now, son, God doesn't hold you to youthful, irresponsible decisions, so don't worry about it.”

An important part of the story here is my daughter Sarah. So, we have six children. We had three during my seven years of neurosurgery residency in Cleveland. I'd come back to Boston Children's to be their first fellow in pediatric neurosurgery. That was about 1991. And my wife was pregnant with number four, which people thought was nutty, even then. We had no idea but when she was born she had some things really wrong with her and we couldn't quite be sure what it was in the beginning.

As it turns out she has a genetic condition called type 1 neurofibromatosis, which affected the development of her brain. It makes it so that tumors grow on most of the nerves in your body, including some really massive ones in her head and neck, which have affected her.

Sometimes they become malignant, so she's had some surgeries.

So Sarah is developmentally delayed and she's very hard of hearing and a bit difficult to understand. But she's one of the greatest blessings of our life, really. She's 32, very eagerly anticipating her 33rd birthday and telling us what she wants her party theme to be.

When I'd been at the University of Kentucky for a while trying to write NIH grants, God just didn't let me go as far as this commitment. Cindy, my wife, she felt the same sense of calling. I started looking at Christian mission organizations. I wound up going to Kajabi Hospital in Kenya to volunteer for about three weeks. There was a surgeon there who was a general surgeon.

He had a passion for children with disabilities, clubfoot deformities, burn contractures, spina bifida, and hydrocephalus, and he was not trained to do these things, but he was doing the best he could. So, I went and spent three weeks with him and showed him how to do things a little better.

Because of that experience, I met a man named Scott Harrison, the founder of Cure International. Scott and his wife Sally had just built this first hospital in Kenya that I was working at. And they had a vision for building orthopedic hospitals for children in Sub-Saharan Africa.

So, I approached Scott and I said, “What would you think about doing a neurosurgery hospital for children?” Scott was himself an orthopedic surgeon. It was a foreign idea to him, but he gave me a shot.



We went sight unseen. We plopped our six children down there in this fairly rural place to help start this hospital, which was called Cure Children's Hospital of Uganda.

The overwhelming majority of kids were babies with hydrocephalus and spina bifida. And up until that time, the only way people were treating infant hydrocephalus was by placing a shunt. The problem with shunts is that they almost always fail.

A shunt malfunction can be fatal, but we developed a procedure that worked well in infants that treated the hydrocephalus endoscopically without placing a shunt. And we were able to avoid shunt dependence in about two-thirds of those kids.

That was a big deal because it had the potential for really saving a lot of lives.

Because of family issues, including Sarah with some things that she needed and some complications she was having, and because I had trained a Ugandan neurosurgeon in all these techniques that I had hired as my partner, God very clearly had us come back to the States against my will.

I didn't want to come back, but it was clearly the right thing to do.

When I first learned Sarah had a disability, it was when I was really in the middle of my fellowship in pediatric neurosurgery. So I was already a trained neurosurgeon.

I was doing an extra year of specialty training in pediatrics. Sarah was born in the hospital that's connected to Boston Children's, the Brigham and Women's Hospital. And for about the first week or two when she was in the NICU, I knew she was very dysmorphic. She was a funny-looking baby.

They couldn't give me a diagnosis. I said, "What's the matter with you guys? Here we are at Harvard University, one of the best medical centers in the world, and you can't tell me what's wrong with my daughter?"

They just didn't know. So finally, after we'd gotten her home, she had some breathing troubles, and she was on a monitor and oxygen, she was feeding poorly, and failure to thrive and I was reading a book about congenital neurologic problems and I ran across this syndrome, which was a kind of rare presentation of neurofibromatosis that involves the face. And I remember telling my wife, that's what Sarah has.

At the end of the day, they biopsied a lump that was in her face at the time that ultimately got a whole lot bigger. And that's what it was. And then they did the genetic testing, and she was completely missing the gene that you're supposed to have.

I think my first reaction to knowing that I had a daughter with a problem was, "God, why did this happen to me?"

That's so trite, right? But people do ask that question. "How is this helpful? If you had to teach me a lesson, don't do it through my daughter. Do something to me, but not one of my children."



I grieved over that. And it didn't help that some of our extended family on my wife's side told us that this wasn't God's will, and our daughter had these problems because we didn't have enough faith, and don't let the devil win and you just don't have enough faith.

And I wasn't very happy about that. That just wasn't helpful. Of course, I prayed that God would heal my daughter. I did, a lot. But that wasn't what he chose to do. In hindsight now, I can see that was actually a wise choice on his part.

Because Sarah is Sarah. I remember coming to the decision early in her life that I was going to stop praying that God would change Sarah. Because if God healed Sarah, she'd be a different person. She would not look remarkable like she does. She wouldn't have the same mind or personality.

She'd be a different girl. So my praying for God to heal Sarah would have been for me to ask him to take her away and give me a different daughter. That was a good lesson for me. Another lesson for me was how to face the world with a daughter that has not just disabilities, but pretty significant deformities, especially the head and neck.

Your face is a very special thing, and people know you by your face. So from the time she was little... When we had our first three kids, we'd go to the grocery store and people say, Oh, look at the cute baby, you know.

When we would take Sarah out, either people would quickly look away or they would stare with sort of shock or if they're children, they would run to their mommies and say, "There's a monster." And our older three children, Sarah's older siblings, got to where they were pretty defensive about that.

When we went to Uganda people did think that what Sarah was cursed, as they did all the children that we treated with hydrocephalus, spina bifida, anything that was a disability or deformity was considered a curse.

That's just their worldview. As it turns out, I think God sent Sarah to Uganda as much as he did me because people really took notice of the fact that we had Sarah out in public and loved her. And as a family and to them, that was extremely remarkable.

I would take her to the hospital and all these mothers were there. They're often mothers who had been abandoned by the father and ostracized from their family for having one of these "cursed" children, would see that I had a "cursed" child. And they were taken aback by the fact that a rich, American, white guy would have a child with problems and loved her and had her out in public, didn't stick her away somewhere.

So Sara was a real witness in her own right. And whenever I would go back, the first person that the hospital staff always asked after was Sarah.

They didn't ask about my wife or the other kids. It was always Sarah they cared about because she's the one that really made the impression on them.



For Sarah, the way she looks and the way the world perceives her has been the hardest part of her life. Sarah can walk and talk, and she reads at about a fourth or fifth-grade level, and she has stuff she loves to do. She's a happy girl. I should say young woman. She loves children.

She's the favorite aunt to my grandchildren. She's a very happy person. Sometimes I say, "Sarah, I wish I could be like you." She's a lot happier than I am. But for her, going in public, especially with strange children, is a real challenge because she has had so much in the way of laughing and pointing and kids being scared of her.

I think that's the worst thing for her, is when little children are scared of her because she loves children so much. She could do some simple job or employment if she wanted to, but the kinds of things she would like to do puts her in the public eye and that's a real challenge for her.

The other thing she talks about all the time is "Why can't I get married? Why can't I have children?" Her younger brothers, they got married. "They're younger than I am. What's wrong? Why don't boys like me?"

That's the biggest area of suffering for her. It's not the fact that she drools a lot or that she has trouble talking or people can't understand her or that she is very hard of hearing. It's that people think she's ugly.

"Why do they think I'm ugly?" That's the hardest thing for her. And consequently, that's the hardest thing for us too. We hate to see her feel that way about herself.

There's this tendency for all of us, I think, to objectivize people. We see them and we think, that's a good-looking person, or, gee, that's a weird-looking person, and so they look at Sarah and they don't know what box she goes in because she looks so different.

And if they could get past that and learn her lovely and funny personality, they'd stop seeing that. And we've seen that with people. Once they get to know her, they forget about how she looks. Because she's hilarious. And she's just such a fun and wonderful person.

But people don't see that. They see something that they're afraid of or they don't understand. Her favorite thing is her nieces and nephews. So they're all pretty young now. They range from 11 down to 2. And for some reason the grandchildren love Sarah more than anybody. I always say, "Sarah, why do the kids like you so much more than they do me?"

"I don't know." Then she'll laugh because that's special for her that the kids like her better.

How has parenting a child with a disability enriched our life is a really good question and one that I'm still learning from. I'll start with me. I'm convinced it's made me a better person. It's made me more compassionate. It's made me a better doctor. It's made me better with parents of my patients who have disabilities because most of my patients are disabled.

I'm able to relate to families better. And not infrequently I'll bring up Sarah to them. I do a lot of prenatal counseling, especially for parents that have had their child diagnosed with spina bifida,



and I consider it a win when I convince them to have the baby. The majority of those children will be terminated.

But once parents understand that it's a person and it's there, I always try to say if it's a boy or girl, if we know what it is, I'll say, "I'm sure this is a little girl you're really going to love." And I've had mothers just weeping. But it's true because I can say I have a disabled child and it's been one of the greatest blessings of our life.

Now that's hard to explain to people. They don't understand that, and I can't put it into words. I wish to goodness I could. But Sarah is a great blessing in ways that I don't really understand. Sarah was good for our family. She was a point of gravity at which, which sort of drew us all together when need be.

When she'd have surgery and was in the hospital yet again when, or even Uganda and a crowd of children would come around laughing and jeering at her or when Sarah was being really funny at home, you know, Sarah was a part of our common life and was a common bond and she still is.

She made my other children more compassionate. I have no doubt of that. I think they're kinder people than they would have been. At least I like to think so. And Sarah drew my wife and I closer together. Families that have a child with a disability actually have a higher divorce rate.

We've been through a lot of stuff as a family. Cindy and I, we've been married 45 years next month and it hasn't all been easy. But boy have things brought us close.

There is a moment that sticks in my mind that's hard for me to tell. Cindy and the six kids and I were on vacation. The kids were all pretty young. Sarah was old enough to walk. She was maybe five or six. And we went into a place and we got ice cream cones. In those days I was more conscious of what people thought about us as a family. And I frankly was embarrassed by Sarah sometimes. I'm not anymore, but there was a time earlier in our having her that I struggled with self-consciousness. She came out of that place carrying this ice cream cone.

It was dripping all over the place. She had chocolate ice cream all over her face. She was an absolute mess. She was crying. I forget why she was crying. It just was something wrong. And I got angry with her. I hate to admit that, but I got angry with her because I was embarrassed because she was making such a scene.

I've never forgiven myself for that. I didn't do anything bad. I may have yelled at her or something, I don't remember. I just remember being angry and embarrassed and discovering how small of a person I really was. I'm her father and here I care about what people are thinking about me because of her.

As insignificant as that sounds, that was a point that God changed my heart. I think of that as little as possible, but it comes up once in a while. And I will remember that because I was so ashamed of myself.



After that moment it was a process. It wasn't like suddenly I went from being that guy to being a really good guy, a really awesome dad. There was a process of God working on my heart and making me steel myself against the world and not care anymore.

When we would like take her shopping or something, and I knew people were going to be looking at her, God just gave me this ability just to keep walking and just to say, I don't care. This is my daughter. And I think he gave me some courage I didn't have.

What I'd like to say to dads who have a child with a disability, which is, that's a very big box. There's all kinds of disabilities in all different severities. I think what I would say maybe for one is to just remember that right now, this time we're living is a drop in the bucket.

“Teach me to number my days that I may gain a heart of wisdom.”

And part of that is knowing that this is not permanent. Because there's stuff we don't understand. And God has his reasons that seem unfathomable.

It's like Joni. Joni didn't want to be stuck in a wheelchair her whole life. But that's what made her Joni. And there's been so much good that has grown out of that, and God's used that. And Joni's not going to be in that wheelchair forever.

This is a small amount of time. I don't know why God does things the way he does because he's God. But I would say that if you have a child, and it's such a burden taking care of them, or it's embarrassing trying to take them to a restaurant, or you're stuck with multiple medical procedures, having to be in and out of the hospital, that's all really hard stuff. And don't let anybody downplay that. It's really hard.

But at the same time, I would say to believers, ask God to work out his purposes for that in your own life and the life of your family, because he has purposes. I believe that. And you just have to trust him.

I couldn't be a surgeon if I didn't believe in God. I wouldn't want to be because I depend so much on him. You have to understand that takes a long time to become a surgeon. It's hard to describe. The training is hard and long. And you gain skills and confidence and courage just by doing things a lot of the time. And you have to have confidence in what you do.

I do the best I can. I study the cases. I do a lot of homework that families and patients never know about or see. But the other thing is I pray about these patients. I ask God to help me do the right thing. I ask him every night before I do surgery, and I usually name the child by name, help me do the best that can possibly be done for this baby, protect him from any complications, please make this help him and give him a good recovery.

Sometimes, not infrequently, if I'm stuck in the middle of complex spinal cord surgery or something that can be very technically challenging, not infrequently I will pray while I'm operating. For me, for me, the first thing is to just to myself, say, “God, please help me. How am I going to...How are we going to get through this?” And we always do.



My faith also gives me another reason, or maybe the ability to love children and their families that I wouldn't have.

God wanted me to do this. He specifically called me when I was young to be a doctor. And then he specifically beat on me until I moved to Uganda. He just wouldn't let me go. I had no idea of any of the things that were going to happen.

Everything that's happened to me from being accepted to Harvard Medical School as a real nobody to doing something that was able to help a lot of people and the years in Uganda, which I thought were going to be lost years. I told my wife when we moved to Uganda, I said, it's a shame to be giving up academic pediatric neurosurgery but this is what God wants us to do.

And so I thought I would just disappear into oblivion. It turns out those were the most academically productive years of my life. It gave me an entire career that I never would have. So now I'm back at my alma mater on the faculty, you know, as a professor. Who would have thought? A hillbilly Southern Baptist preacher's boy.

I became involved with Joni and Friends on the front end through the New England-area of Joni and Friends. We had been supporters of that for years and Sarah had benefited from their ministry. We got to meet Joni one time and it happened to be Sarah's birthday and Sarah was there with us. And so Joni, when she found that out, she had everybody saying happy birthday to Sarah, which Sarah still talks about.

I think there are parallels between Joni's story and Sarah's story and millions of other stories. As Sarah, my daughter, calls it people with troubles. People with troubles that they never would have chosen, or their parents wouldn't have chosen for them. One of the scenes in the Gospels that I think is somewhat relevant is when Jesus was with his disciples, and they saw a man born blind.

They said, Lord, who sinned in this case? Was it this man or his parents? And Jesus said nobody. It's so that God would be glorified. Now, most people take that story as being the lesson is, people don't suffer because of sin. They do, but it's not the reason that you were born blind.

It's not because your parents did something bad and God's punishing them through you. That is part of the lesson. But I think the underneath of that lesson is, this man is the way he is to glorify God. Now in this case, God was glorified because he was healed. But that's not the only way to glorify God.

And this man had been blind for how many years? He was an adult. So I think God, we just we have to realize that, and this is trite, but I'll say, his ways are not our ways. God made Sarah. I have to trust that. I don't think it was an accident.

God intended Sarah. And I can in hindsight see many good things about that. And I think Sarah is far happier than a lot of "normal people." Far happier. I know some brilliant, physically fit, successful people that are miserable. If I had to pick who to be, I'd be Sarah.





I think that's a cavalier thing to say, but you know what I'm getting at. In her heart, she's happy. To think that anytime something bad happens to you, or if you have a child with a problem, to think that's not God's will is really, I think, speaking out of turn.

God just may well have his reasons and he's in control. And so for me to tell God, I don't want Sarah, I want you to give me a different daughter, which is Sarah being healed is what that is, I think that would be somehow blasphemous in a way. Now, I prayed for God's will to be done and I said, Lord, if there's any way that Sarah can not have to suffer with these things, please change her.

But I just, I think that wasn't what God wanted to do. As I've heard it said, God's not a cosmic bellhop. He doesn't do things just to please you.

He's got much wider purposes, eternal purposes, that it's not all about you. It's about a lot of other things, much of which we don't see.

I have to say that the favorite part of my job is seeing the parents be relieved and happy and thankful that their child is doing so well, and I've been able to contribute to that. That's really what, as they say, makes me get up in the morning. Surgery is interesting, and science is interesting, and neuroanatomy is interesting, and I love teaching, and I like writing papers and things, but, the thing that really stirs me is that.

I get a chance to follow these children for years and develop relationships with them and their parents. And I love that. Many of them I love, and they love me. Oftentimes little Susie that I operated on five or six years ago, the parents will say, as they do every year, can we please get a picture of you with little Susie on your lap?

And I'll say, sure, no problem. So I tell people I'm on some of the best refrigerators in New England.

Crystal Keating:

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