

An Orange Socks Story - Mindy and Chris: Spina Bifida, Hydrocephalus, and Club Foot

Interviewed by: Dr. Gerald Nebeker, President of Orange Socks

Gerald: Chris and Mindy took time from their busy lives for an Orange Socks interview about their son, Camden. When prenatal tests revealed that Camden had spina bifida, hydrocephaly, and clubbed feet, their high-risk doctor encouraged them to have an abortion. I met Camden during the interview, in fact, it's him you hear interrupting his parents during our time together, just like any other two-year-old would do. I'm glad they didn't follow that advice, and so are they. Tell me about when you found out that Camden had issues, and what were your reactions?

Mindy: He was our fourth, so it was just a routine ultrasound and it took a long time, she was spending a lot of time on the brain and on the back, but I just assumed nothing was wrong and went home. And our doctor called us that night and said we should probably sit down for the news, um, he said, "We did find some things," and proceeded to tell us that Camden's spine hadn't closed sufficient-all the way at the bottom. So that was-showed the sign of spina bifida birth defect. And there was also dilation on his brain, which was a sign of hydrocephalus. I had placenta previa, and then, so it was just a whirlwind, I didn't really know what to say. I just, I remember saying, I think, "I don't know what any of that means, but I know that it's going to be okay." And our doctor was great through the whole thing, you know. He believed in the same thing as us, that babies come the way they are supposed to. So, I had a lot of peace with going to him, but then he sent us to a high-risk doctor, and that was a completely different experience. That doctor also found that he had clubbed feet in both feet. And he was the one who told us over and over that we had up 'til 26 weeks, in Vegas, to abort him. And that he probably wasn't going to have a great quality of life. Hydrocephalus was going to mean brain damage, probably wasn't going to walk, and all the worst-case scenarios. So that's when things got a little, just unsure, not knowing how things were going to turn out. But he did give us the option of doing a fetal surgery in utero, and that's what we ended up doing. Our hopes were that going in and closing up Camden's back would prevent more nerve damage to his exposed nerves, for the rest of the 20 weeks that I carried him. So, we did that and that was a miracle, and we ended up delivering him at 32 weeks, 5 days. So, he came early, but he's been amazing ever since, he hasn't had to have a shunt for his hydrocephalus. He did, 2 weeks after the fetal surgery actually he had what was called a Chiari malformation, and that's where his brain was being pulled down into his spine, and he had the worst grade of it in-utero, but after the fetal surgery, it went back up to, I believe, a zero

Chris: Grade 1

Mindy: Grade 1, yeah. Which was awesome. He doesn't walk yet. We've cast him for his clubbed feet, but he's seriously changed our family in ways that we are so grateful for.

Chris: At first, we were scared. We kind of went through the being scared, and then not really knowing what this was, and so we made the mistake of doing research online. And I quickly found out that wasn't the best way to get answers. And so, for me it was just the unsure, and then I got kind of tangled up in a lot of the research. And then I found peace when we found our, our Facebook group. And, people that had been through the fetal surgery were able to answer questions and kind of put our minds at ease about, you know, his outcome was gonna be great. There's nothing, that is impossible. In the situation, you don't have to feel helpless. So, we got a great deal of hope once we connected with that group, so.

Gerald: What has been the hardest thing for you?

Mindy: I think the hardest thing for me, the whole time I was carrying him, was just not knowing how he was going come. Because with spina bifida, they call it the snowflake birth defect. Every single child is different, there's no two the same, they're all affected differently. So, it was hard for me to just not know that, and to not have control over, "Okay this is what we can expect when he is born." And, I mean, even now we still don't know what things are going to be like in a couple years. We just take it day by day, month by month, year by year. And he just, I think all parents with spina bifida kids can share the same thing, that doctors can't diagnose the way you feel, and they can't diagnose how much these kids just overcome everything that they're told they can't. The hardest, probably for me, is watching him go through surgeries. And in his first year of life, it was just a lot of appointment-doctor appointments. I would take him weekly to get his feet casted, and just, I don't know, watching him go through that. Getting them taken off, going, he had, he's had tendon releases, and, you know, the brain surgery. Like, you can't get prepared for watching your kid get rolled off to the OR. So that's probably been the hardest for me, but it's been nice 'cause ever since we bring him home, he's just back to his happy self. But the appointments are probably a little rough, and still not knowing, we still don't know if he'll ever walk, but we try.

Chris: I guess it, I have the, both. I see what she goes through, with all of the, medical records and things that need to be sent around to, to get different coverage. And, I see how happy he is, and it's been amazing to me to just be able to focus on the things that he-that he does, and the happiness that he does have. And how we've learned that, you know, his walking is not going to bring joy to his life, his joy is from all the other things he's able to do. We hope that he can have the option to walk a little bit if he wants to, with a walker. But I guess since I've been able to not focus so much on, "Well he may not walk," the most difficult has been just seeing kind of Mindy go through it. And, you know, Camden is so happy, so it's hard for me to really focus on one real negative about having him.

Gerald: I can see how delightful Camden is, tell me about the joys you have experienced.

Mindy: I think the joy that he brings to everybody around him. It's been really cool. You know, I understand, like, from before him, kind of the uncomfortableness a little bit in seeing children with disabilities and not knowing exactly how to interact. But now having Camden, you see the opposite of, "Please, come, talk to him, come see how happy he is, come ask. Ask him questions," you know, "don't, don't be scared." And he does, I go to grocery stores, he talks to everybody around him. And so, I think that, like, I feel his mission is to bring light to the world, just to make people happy, cause that's what he does for us. And seeing him when he's casted or when he's had things that doctors, you know, put him through, he doesn't care, he doesn't let it get him down. So, it like, for example, the last round of casting he had done, he was about one, and he had already learned how to crawl, and then he got casts put on. And I was so worried about that. I thought this is just going to completely tear him down, but he figured out another way to crawl. And he always finds a way around something and doesn't get down about it. So, it's been a lesson for us, for sure.

Chris: One of the biggest joys has been just being with him, and I feel it when I'm with him, I feel the light that he brings to the world, and to my life. He's always just happy, and so I definitely feel that. And then when we take him around, I forget sometimes because when I'm not with him, you know, people just go about their business. But when I'm with him, I get to see the best in people, and I get to see people's compassion. Human kindness at the highest level because people truly care. I feel like our society truly cares about these kids that have challenges. And I get to see it in their eyes and their faces when they come up, and kind of want to know, or want to shake his hand.

Mindy: Yeah, it's not too common to see a two-year-old wheeling around in his wheelchair, you know?

Chris: Yeah, and she has a friend who said it's kind of like, taking a clown around with you all the time. Everybody is so interested, they're like, people are like, "Wow, that's a clown, I want to see, that's cute, I want to look at it." And so, we've embraced the positive side of, instead of, you know, being embarrassed, or wondering what they're thinking. We just try to look at they're being kind to us, and they're being kind to Camden. So.

Gerald: So, tell me how Camden has impacted those around him.

Mindy: How hasn't he? You know, it's, I've had concerns, I think as he gets older, noticing that he's different. You always worry about that day where he's like, "Why can't I run after my older siblings?" But I've seen, I feel like we're so lucky to have him because our older kids are 8, 6, and 5 and they, they're his biggest fan and they've never treated him different. They've always included him in everything they do. And I think it's brought out an understanding and compassion in them and how to embrace other children at school or out in society that have disabilities. They already have that love for them, from Camden. And I think he's definitely

unified us, he has definitely increased our family's faith, just from everything we went through to bring him here, there were a lot of miracles that happened. And I believe it was from a lot of prayers and it strengthened our faith in God's plan for us, and our family, and he's definitely changed us all for the better, yeah.

Chris: Like all of our children have, it's rounded us out, and this is, I feel like there was a part of my heart and a capacity of love that wasn't there before him. And once we had him, it's like my heart grew a little bit bigger. And so, he's made me a more compassionate person, and so the amount of gratitude I have that he has changed me, is pretty profound.

Mindy: I also think he shows us there's nothing we can't handle, there's nothing too hard that we can't handle. Just watching what he goes through, but also just what we've all gone through, really, with him, along with him. Not just him, but us as a family, like, his last month before he was born, my water had already broken. So, I was in the hospital for a whole month, and I wasn't able to be with Chris and the other kids. And it went through all of December and Christmas and everything. And there were so many low points in that where I was like, "This can't get any harder," but we always made it through. And I think it's really shown us, there's nothing too hard, there's nothing we can't handle together.

Gerald: What advice would you give others who find themselves in similar circumstances?

Mindy: I always tell them that God is in control over what any doctor tells you. And, kind of, forget what they tell you, and just know that no matter how your child comes, you are going to love them more than you can even imagine. And you will have doctor appointments and things, but together you will make it through, and you'll have a strength given to you that you've never experienced before. And your child will amaze you with everything they will do, and know that they will conquer everything that is told that they can't do, they will. So be excited for that day you get to hold them. You know, I never tell them it will be easy, it won't be easy, but it will always be worth it.

Chris: I would tell them to find comfort and peace, and the things that you can be sure of. That, you know, the things you have control over, and that is just your perspective, and your focus, and your attitude. I think if you try to figure out all the unknowns about the diagnosis, and try to speculate about how your child is gonna end up when they finally do come, that's where the fear is, is in the unknown. And if you can find peace, in just the things we can control. We have today, we have this next appointment, we have this moment to focus on what we can do best for our child. And with us, there were so many unknowns, that I think that's where I got the most stressed and worried and fearful. But when I just focused on, like Mindy said, you know, my Heavenly Father, and my faith and the miracles that we were seeing. And all the people around us that loved us and were serving us, everything changed. My perspective changed, and we were

able to get him here safely, and I got to see the best in so many people around me. So, I would say, just enjoy the ride, have faith, and be at peace.

Gerald: Is there anything else that you would like to share?

Mindy: Definitely find a group, connect with other families, for sure. We got to meet a family before the fetal surgery. I think seeing their child was a turning point for us.

Gerald: I appreciate learning so many words of wisdom from Chris and Mindy. They have certainly done what Chris advised and found peace in what they could control. And what Mindy said, that it won't be easy, but it will be worth it.