

An Orange Socks Story – Cindy, Mike, and Evan: Spina Bifida

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: It was my privilege to have an Orange Socks interview with Cindy and Mike, the parents of Evan, who was diagnosed with spina bifida in utero. Cindy and Mike were strongly encouraged to abort Evan. They're glad they didn't, and I am too, because I had the chance to talk with Evan, who is now 29 years old. How did you find out that your baby had a problem?

Cindy: Well first we took the alpha-fetoprotein test, and the doctor called and told me that it was three times higher than normal and asked me to go for further testing. There are a lot of false positives with that test, and I was pretty convinced it was not a problem. My due dates were off, I'm having twins or something else, I totally convinced myself. Having had five normal pregnancies, I wasn't expecting anything. So, we went three hours south of where we lived to a place where there are higher levels of medical care and did a high-level ultrasound. During the ultrasound, it got really quiet. I was looking at the doctors' faces, and I knew something was really, really wrong. It stayed quiet, like, forever, a very long time. When they were done looking, they told us the baby's ventricles were enlarged and that he had spina bifida. It was pretty devastating.

Gerald: What were your thoughts, Mike, about the diagnosis and what the doctors were telling you?

Mike: It was rather devastating. I will have to say that was one of the worst moments in my life, just watching the doctor moving the image on the ultrasound and taking pictures. He was quiet, but he was silently shouting, "Something is terribly wrong with your baby." The next thing that we faced were people telling us to abort the baby, even on a follow-up exam two or three weeks later. We were strongly admonished to make it a matter of prayer, that it had to be our decision because we would have to live with that decision. Obviously, we decided to keep the baby because that "baby" is almost 30 years old, and he's with us right now.

Gerald: That's great.

Cindy: I'll just share one more thing about something that was heavy on my mind when making our decision to not terminate our son and that was, "How do you tell your other younger children that there's something wrong with this baby? He might not walk. We don't want him in our family. We're not going to continue this pregnancy." To me that tells them that you had better watch out because if something happens to you, such as an accident or you can't walk or something is wrong with you, then your life isn't worth living anymore. I wanted my children to know that every single life is worth living, no matter what. That was important to me. I think it's helped them to be stronger in life. They are very compassionate people because they know the value of life.

Gerald: So, what have been some of the challenges, Cindy?

Cindy: Surgery. spina bifida surgeries are kind of hard. With Evan too, I think those are some of the hardest things. When he was born, he stayed 17 days in the hospital, and I missed my daughter's first day of kindergarten. You feel pulled sometimes. You have to set your priorities with your children. I don't really think anybody feels bitter about it, they understood, but that's kind of hard on a mom. It was hard to hear the doctors be very negative to begin with. They tell you all the worst it could be. They didn't want to tell you how good it could be.

Gerald: That's an interesting comment.

Mike: Now one thing that helped us immensely after he was born was that we were referred to another pediatrician. The first pediatrician we had was very negative. She was one of the stronger advocates for abortion before the birth. After Evan was born, a friend of ours who was a nurse recommended a great young pediatrician who had already been credited with saving other babies' lives. He was a very positive doctor.

Cindy: He said he admired us for continuing with the pregnancy. Evan did come home from the hospital with a really rare kidney disease that was diagnosed after he was born. It was very life-threatening. He was a medically fragile baby. This doctor was amazing. Having a good doctor really helped us, one who understood how precious Evan was to us because not all of the doctors understood that. This life is precious, it's important.

Gerald: So, tell me about the joys. You obviously made a decision to keep the child, and as you said, Evan is here, and we'll hear from him in a minute, but what are some of the joys?

Cindy: His laugh and the laughter we have with him.

Mike: There was one day that I came home from work, and my other kids described a time Evan was watching a movie and they thought he was going to pass out, he was laughing so hard. For every tear that we've shed, there have been a thousand cases of laughter and joy. We are very proud of Evan. One day he was watching a documentary on TV with scenes of disabled people like himself, but they didn't have wheelchairs so they were just scooting on the ground. Do you remember that, Evan?

Evan: Yes.

Mike: Maybe I could let Evan tell you more about that, but for his Boy Scout Eagle project, he decided he was going to collect wheelchairs, clean them up and donate them to a place that could donate them forward.

Gerald: That's great. So, what impact has Evan had on your other children and extended family?

Cindy: I think that we realized it's okay for everybody to be different. We all have our differences, and that's okay. We don't take the little things for granted. We can get up and put on our pants in the morning, and some people can't do that, and that's okay. Everybody really likes Evan. He's probably everybody's favorite, I think.

Mike: They say he's their favorite little brother because he's the youngest in the family, so they can say that.

Gerald: If I were to come to you asking for advice, saying, "We've just been diagnosed with a child with spina bifida in utero, and you've been there." You've had how many years? Thirty?

Cindy: It's been 29 and a half years.

Gerald: Almost 30 years' experience, raising a child with spina bifida who is now an adult. What advice would you give me?

Cindy: The first thing I would tell you is congratulations! You're having a baby! Babies are precious no matter what! And it's a baby first, the disability, the birth defect, doesn't come first. You are going to feel love for that baby that you have never felt before. They're going to grow up really fast. Enjoy the baby part of them. Don't let the diagnosis overwhelm everything. Enjoy the baby.

Mike: Seek out positive doctors and nurses who are going to help you along, especially during the terrible months between the time of the diagnosis and the birth. That would help. Rely on your faith. I don't know how anybody who does not have faith would be able to do it.

Gerald: That's great. So, Evan, your parents made the decision 30 years ago to keep you, and now you're here. Did you know that story?

Evan: Yes, I did.

Gerald: So, what advice would you give to me if I were to tell you I'm going to have a child with spina bifida?

Evan: I would tell you to keep him.

Gerald: And how has your life been?

Evan: It's been good.

Gerald: What are your favorite things to do?

Evan: Well, I am a Star Wars fan, and I'm also a whale fan, and a fan of the Mormon Tabernacle Choir and Jim Nabors.

Cindy: What do you do? Tell them some of the things you're involved in.

Evan: I'm also involved in a group of young singers called The Joyous Voices in Jesus that involves young adults like myself and other adults that have disabilities, different than mine.

Gerald: Do you have a good life?

Evan: Yes.

Mike: Tell him about hiking a ball around.

Cindy: What sport do you play?

Evan: I play a sport called power wheelchair soccer. It involves a power wheelchair, a metal guard and a ball, maybe 13 inches bigger than a normal-sized soccer ball.

Gerald: That's great.

Evan: It is great.

Gerald: It is great!

Cindy: He's had a pretty full life. He's traveled cross-country with us twice, seen a space shuttle launch, held an alligator and seen the Grand Canyon and geysers at Yellowstone.

Mike: We have an awesome Make-A-Wish. Do you want to tell him about your Make-A-Wish?

Evan: For my Make-A-Wish, I got to help a man named Al Roker do the weather. That's not the only thing that was a part of the Make-A-Wish, the other part was to see the Statue of Liberty.

Gerald: That's neat.

Mike: Helping Al Roker on the Today Show was on live TV.

Gerald: That's fun. How fun!

Cindy: On the Today Show in the morning.

Gerald: I can tell that Evan has a full and rich life. He's been a blessing to his family. And meeting Cindy, Mike and Evan has been a blessing of mine.