

An Orange Socks Story – Krystal and Dusty: Spina Bifida

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I had the privilege of meeting with Krystal and Dusty, the proud parents of two adorable little girls. The youngest, who you will hear in the background of this interview, and the oldest, two-year-old Amnesty, who has spina bifida. They were encouraged by several medical personnel to abort Amnesty. Not only did Amnesty have spina bifida, but she was also diagnosed with a heart defect in utero. That heart issue was monitored throughout the pregnancy and represented a major concern. Miraculously, when Amnesty was born, no heart defect was found. Amnesty did have to have surgery to repair her spine and insert a shunt in her head to drain excess fluid. Amnesty's birth and life have been so celebrated by Krystal and Dusty, that they founded Irregulars for Christ, a ministry, "dedicated to giving hope to the hopeless by spreading the testimony of God's grace." Krystal, when did you find out your daughter had a disability?

Krystal: They told us that her spine didn't fully form properly early on in the pregnancy, and it didn't look like she would have much function with her legs. There were maybe some other issues involving her brain being squeezed by excess fluid, possibly causing brain damage, as well as some bladder issues which would lead to a lack of quality of life.

Gerald: What advice did they give you?

Krystal: To explore our options, but I never got the sense that they meant all of the options. I felt like that statement meant to abort the pregnancy, to explore the option of aborting the pregnancy.

Gerald: They didn't say that explicitly to you, or they kind of hinted that way?

Krystal: Well, we saw several doctors throughout the pregnancy, and they discussed variations of how they would word it. Sometimes it was just flat out the word "abortion," but other times we would hear some encouraging things and some encouraging stories. The majority of it was that we were still early enough in the pregnancy to end this and to not have to go forward with all of the complications ahead.

Gerald: So Dusty, what were your thoughts when you found out about the diagnosis and the advice that you were getting from the medical professionals?

Dusty: At first it was just very, very terrifying to get that initial diagnosis and hear all the negatives. Not only did we hear about all the possible complications, I initially remember that they pushed taking the easy way out rather than going through with what might be a long-term issue with our daughter and her complications. In my memory of it, there was a lot of worry, a lot of fear instilled in us and not a lot of hope for what might be.

Gerald: Krystal, what were your feelings at this time?

Krystal: I remember it was almost surreal. We left the office, and I was in shock. I wanted to have a baby, always wanted to be a mommy, and never thought this would be the outcome. I remember calling up my sister who is my best friend, and telling her that our baby was broken, and that there was something wrong with her. I felt hopeless. I felt like a victim. I felt like in the moment, it just seemed impossible.

Gerald: So, you obviously didn't end the pregnancy, she was born. What have been the hard things that you've had to deal with so far?

Krystal: She's two now, and the hardest things are just the fact that she's two, not anything to do with her diagnosis. She's just going through a stinky phase with her attitude like a normal two-year-old. But throughout the last two years, the biggest scares with her have been when we have issues with her shunt.

She has a shunt in her brain, and it was something they had to install because of the excess fluid that was building up. Thank God, praise God, she's never had any issues with it. However, anytime she has a fussy outbreak or throws up or something, the first thought is always, "Oh my gosh, maybe it's her shunt malfunctioning." That's been probably the hardest thing. There have been nights when I've put her to bed, and as her mommy, I am always scared that I'm going to wake up and maybe she hadn't made it through the night. Just losing her, the fear of losing her. I love her so much.

Gerald: How about you, Dusty? What have been the hardest times for you?

Dusty: Well, initially when she was born, she had to have surgery to close a hole in her back and put her spine back in, and then days later another surgery to put in her shunt, so we were in the NICU for quite some time with her. We couldn't really touch her or hold her because she was so fragile, and as first-time parents, we really didn't know what we were able to do or what might break her. She needed constant physical therapy, and she still does need some physical therapy. Initially, her surgeries were the scariest part.

Gerald: What have been the joys?

Dusty: There are so many joys, being a father to this sweet little girl, who is just like other kids in all ways except that she's not able to walk right now without the assistance of walker. She's just so sweet, and her testimony has touched people's lives and also made us better parents. Going through her issues and having to be so trusting in her situation and so involved every step of the way, I feel like it has made us appreciate our daughter even more to where it's made us more loving as parents. It's made us more involved in her life, strengthened us and made us see the importance of being present in such a huge part of her life and not moving her to the side or just going through the motions. It's made us more involved parents. I know it's made me a more involved parent.

Gerald: So, Krystal, what have been your joys?

Krystal: Well, Dusty said most of it. She makes me want to be a better person. She reminds me that my little struggles aren't that big of a deal. She's our quiet daughter. The other one not so much, as you might know. She's just very sweet and fragile and loving. There's just something about her that you cannot forget. She brings joy to my life because she made me into this new person. I am who is much more laid back and much more in the moment. I am just grateful for the struggles in life that I've encountered because I can see she's the direct result of the beauty in the struggle. Amnesty is our joy.

Gerald: So, Krystal, what has been the impact of your daughter on your extended family, your friends and your neighbors?

Krystal: We have quite the extended family because we're in ministry, and we travel and share our daughter's testimony about choosing life and trusting God with her. As far as our personal family goes, I've seen both sides where it seemed pretty hopeless, and to see the hope that's come from her life has been a real eye-opener. What else seems hopeless? Maybe it's not as hopeless as I thought. Our family just loves her to pieces. As far as the outside extended family in ministry, we've literally seen people impacted by Amnesty's story who have chosen life because of her story. People have reached out to me and said, "I have a really sick baby diagnosed with some really bad diagnosis, and your story has given me hope. I don't know if it will be the same outcome, but I know that you have been strengthened by it, and so have I." We've met people who have chosen life for their babies. We try to help those people to make that choice a little easier. But overall, it's been a very positive impact on the community and on our family.

Gerald: Dusty, do you have anything to add to that?

Dusty: Yes, one of the things apart from the spina bifida diagnosis was our daughter's heart diagnosis where she had all these heart issues which became the main issue even above her spina bifida. The doctors monitored that weekly up until the day that she was born. Then, the day that she was born, her heart defect was completely healed. Her heart was perfectly fine, and that testimony of the healing of her heart has

given people hope that there are miracles that still happen today, that there are healings that still happen today. Just because a doctor tells you one thing is going to be the way that it is, it doesn't always turn out that way. That has given people hope. I've seen that impact people's lives in our ministry travels. I've also seen it impact lives in our immediate family with the spreading of hope that we have a God who still does miracles today.

Krystal: I just wanted to share that it seems like lately, every pregnant person I come into contact with has some kind of thing the doctor is monitoring on her baby. I just want to point out that doctors are wonderful, and if it weren't for the surgeons who operated on Amnesty, she wouldn't have survived. I say all that I know that some of these doctors can be really scary, but we're also grateful for the other ones. The doctor's job is to look for issues and solve them. So, that's what happens with a pregnant woman. Sometimes, those issues really are there, but sometimes they're not, and there's really no way to tell until that baby comes out. I just want to put that out there that we never really know what's going on with the child until they're in our arms. We don't want to take away that chance to hold our baby based on a, "What if?"

Gerald: That's terrific advice. So, if I came to you and said, "Our 20-week pregnancy check-up revealed that we had a child with spina bifida," what advice would you give me?

Krystal: As a woman of faith, I would say to take it to prayer and lift it up to God. I would also say to get into a community of other people who are in a similar situation because they can answer real questions, even down to the specific diagnosis I would say. Because that parent or friend is going to be able to tell you the reality of it. A doctor only sees that initial snapshot, or snapshots throughout the whole progress, just little bits, but a parent will see it through. Immediately get into some resources of some real families, really walking it out and asking real questions, and then also I would say to even take that to prayer because everyone's had their own situation. For example, spina bifida, and I'm sure this is the same for a lot of other diagnoses, is case by case. They're all very different. It's not a textbook thing, so also keep that in mind.

Gerald: How about you? What advice would you give me, Dusty?

Dusty: First, as a man of faith, I know that my faith rests in a God who heals, who can see things through and who knows more than I do. As Krystal said, a doctor is giving you a snapshot of what could be without knowing. He doesn't know what's going to happen, only what might happen or what could happen, and they're giving you insights of worst-case scenarios to cover their end of insurance and things like that. In my mind, just as Krystal said, get in a community of people who have been there and have seen these cases through, who have a child themselves. One of the things Krystal did was join a Facebook group for spina bifida and got information from actual parents who had a child with spina bifida. They asked some questions, and she got so much good advice from them to just pray and be in community with others, to not go through it alone. We're not meant to walk through this life alone, we're meant to be able to lean on one another. Be in community with like-minded individuals, and even other individuals who have a child who might have the same diagnosis.

Gerald: Very good. Thank you. I was honored to spend time with these two positive and dedicated parents who are working so hard at spreading the testimony of their family's lives. I enjoyed meeting Amnesty, who I had the privilege of holding briefly for a photograph.