An Orange Socks Story – Amber and Justin: Down Syndrome

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

Gerald: What a pleasure it was for me to meet with Amber and Justin and have an Orange Socks interview. I was looking forward to speaking with them because I had met them previously and knew a little of the heartwarming story of their son, Finneas. They found out that Finneas had Down syndrome in utero and were encouraged to abort him. I had the pleasure of meeting Finneas at the interview, what a cute little guy. I can tell he is really loved by Amber and Justin. Tell me how you found out that Finneas had Down syndrome.

Amber: We got our first inkling at 14 weeks. I had gone in for an ultrasound for something else, thinking I had cysts that were bursting or something because I was in pain. They noticed that my sacks weren't growing together, and that indicates a chromosomal abnormality. At that point, they told us it was likely Trisomy 13 or Trisomy 18, both of which either don't come to term or you lose babies after birth, or Trisomy 21. That was when they first talked to us about abortion because there was an inkling that something was very, very likely wrong. They offered to do chorionic villus sampling right then because I was on the border of being able to do that, and we didn't feel like we wanted to do that because of the risk of miscarriage.

Gerald: Based on the initial test results, they were told to have an amniocentesis, but opted not to because of the risk of miscarriage.

Justin: Well, right at the beginning, when trying to get pregnant, we knew the risks. But of course, we thought, no, we'll be fine. Going into it, our minds were already made up, we weren't going to change our minds about abortion. We knew the possibilities and risks were there, and when we found out that there was something wrong, without really knowing the extent of it, Amber decided to dive really into it and find out more about the Trisomy 21, Trisomy 18, those types of defects, and we just kept going.

Amber: I think right at the beginning, when they left me in a room because they weren't ready, and the doctor couldn't come in right then, the person who happened to be able to do the CVS testing was actually in the hospital that day, so they kept that person there just in case. The whole process was probably four hours between the time that they first found the problem and I talked to the doctor, and the time I waited for the genetic counselor to get to the hospital. They told me to call him because decisions needed to be made.

Gerald: I understand this was very stressful. Tell me how you felt.

Amber: I think I was so freaked out, thinking about it. It was almost like I couldn't even hear. When she left to get the doctor, I knew something was wrong, but they had just shown me fingers and toes and everything for the first time. I was so relieved, I was like, "Oh baby's fine!" We didn't know he was a he at that time, but I was feeling so good, and then I knew that something was wrong. It’s hard to explain, but somebody is talking to you, and you can't hear and you can't process because you are so scared and worried. When Justin got there and we met with the genetic counselor, I think he left to throw up in the bathroom, right?

Justin: Uh, yeah.

Gerald: Amber's situation was different for many women, she has MS.

Amber: I have MS, and I was thinking, "How am I going to take care of this kid?" We didn't really know. We'd never grown up with anybody with Down syndrome, we didn't have any friends, and we were scared half to death.

Gerald: Amber's thoughts turned to her other children.

Amber: I remember leaving the hospital that evening about 6:30 when we finally got everything settled, and I remember turning to him as we were waiting for the valet and saying, "Will they love him?" I was worried about the older kids, wondering if they would still be excited, would still feel that connection to him. It was scary to me, but that was one of my first thoughts, "Are they going to love him?" Our family. I wasn't worried about aunts and uncles and grandparents and all of that because I knew. But I thought about these kids, how are they going to react because they are so excited, are they still going to love him?

Gerald: Tell me your reaction to the news, Justin.

Justin: I did have a stress reaction. Yeah, I do remember that. I was shocked. I wasn't shocked because I was expecting something, but like Amber said, I didn't know anybody. I had seen people with Down syndrome, but really had no connection to anyone, family, anybody. So, it was an unknown for me. Not knowing how beautiful it is. It was very scary because I was afraid. I was afraid at the beginning because Amber has MS, and so it was a high-risk pregnancy to begin with, and then when we did finally get pregnant, it was kind of a one-shot thing. When it does take, and then later on we find out, I'm more nervous now for the love of my life, I don't know what's going to happen. This is going to cause stress, and I think that's what my reaction was, dealing with something that's an unknown. And now that also that my wife is struggling and again thinking of our children. I remember her sitting there and telling her, "Yes, our kids will love him." But then again, it was the unknown. It was some positive thinking, but more nervous not knowing exactly what to expect.

Amber: Well, and all they tell you, honestly, the genetic counselor, the doctor, everyone we talked to that day, is all of the negative things.

Gerald: What did the doctors and genetic counselors tell you?

Amber: They tell you how bad their IQ is going to be. They tell you basically what a burden and what an unknown and what a negative thing that it could be. There's no positivity other than to say, “But you never know, there's no way to know.”

Justin: I agree with that. I don't know if it’s total negativity. I think it’s just facts, neutral, but you're right that really, they spent almost all the time on how much of a burden it is instead of...

Amber: And they could have all the health problems and all the scary stuff.

Justin: …Instead of how beautiful and wonderful it can be.

Gerald: So how did the other kids take the news?

Amber: That's probably the hardest thing for me to talk about. They are probably the biggest, most wonderful things that could have happened that helped me process through. Because every single thing that I thought of as a negative, my older kids somehow turned into a positive. It didn't matter what it was. One night my daughter, who was 12 at the time, wanted to know what he was going to be like. We were talking through some of the challenges that might come as far as motor skills and walking, and she said, "Well then, we'll just have to help him, it's not a big deal you know." And I said, "Well it might be a thing where he's not going to necessarily grow up all the way. He's going to grow and then there's going to come a point where he'll still learn and do different things, but he may not..." I was trying to figure out how to explain this to a 12-year-old so that she understood and so that it’s not scary. She kind of got this screwed-up look on her face and said, "So, what you're telling me is that he's going to be a boy trapped in a man's body?"

Justin: She did, she did say that.

Amber: "Actually that is kind of what I'm saying." And she said, "Why didn't you just say so?" Then she paused for quite a while and that worried me, that scared me. It was not knowing exactly what was going on. Then she got this huge smile on her face and said, "That is awesome!" I said, "Why? Why is that awesome?" And she said, "Because he'll always be fun! He'll always be fun." And there were so many moments that were like that. They just had a way of flipping things just upside down. They see what's there instead of all the extra "What if’s?" and this and that and the other. They don't go beyond, and it was a huge blessing to me, those older kids. They were so protective of him that we couldn’t even talk about having heart problems. He had heart problems and he had issues, and we couldn't even talk about that because my daughter would just say, "There is nothing wrong with my baby, don't you dare say there is anything wrong with my baby." And they are like that even now.

Gerald: What were your thoughts, Justin?

Justin: I'll share a couple of things. One is how we told them that he was going to have Down syndrome, and I remember we did this as a family. We got together, sat down and told the children about him and a little about Down syndrome. What I found interesting is that it was fun because Morgan did try to understand Down syndrome. What is it about? She knows that there's a certain look, and she studied that much like Amber does. When we would go out to places, the kids would pick them out left and right. "Hey, they have Down syndrome. Hey, do they have Down syndrome?" "Yeah." They would point them out, and then Morgan would push us to go and talk to the family. We were at the mall, and there was a cute little baby.

Amber: It was like a year old.

Justin: Yeah, it was like a year old. "Dad, they've got Down syndrome. Go talk to them." So, we would go talk to them and tell them that we were expecting, and we got to know them a little bit. I don't think we've seen them since, but it was just fun to see how the kids became part of that and how it was kind of a new thing for them. Wyatt was just cool with anything. He just said, "Yay! I'm getting a brother. I don't really care." But I don't think he really understood the implications.

Gerald: How old was he?

Justin: He was eight.

Gerald: You have a fun story about your son being concerned who Finneas would look like.

Amber: The one thing that Wyatt was really concerned about is that he wanted a twin so that I couldn't tell the difference between the two, even though there were eight years between the two. When he started looking at all the pictures, he was really concerned that he would have a brother who didn't look like him. He was really tense about that, really, really worried about that. We had to explain that he's going to look like a lot of other kids that have Down syndrome, but he looks like Wyatt! You look at baby pictures, and you look at pictures of Justin, and even when I sent my 3D ultra sounds to the girls at work, they would say, "He looks just like Justin." He looks more like us than we ever thought he would, and Wyatt loves that. He loves it when people tell him that Fin looks like him.

Gerald: What's the hardest part of this?

Amber: I don't know because I think that we have come to see it as a blessing, I guess. So, it's kind of hard to say what we think is hard. One of the things that is hard for me is that I worry about how people will see him in the future. When he's not a super cute baby, and grocery shopping takes me three hours instead of 45 minutes because he has to talk to everybody and everybody has to see him and talk to him.

Justin: He's very sociable.

Amber: He's really social. But I wonder, as he gets older, if people will have that same reaction to him. I worry about how the world will be with him, and that's still hard for me. Sometimes, the “what if’s” are hard.

Justin: I don't know if this was hard, but this was very shocking to me, when he had some health problems and had open-heart surgery. I think maybe the doctors could have better prepared me for how he was going to look after the surgery. I walked in after they were done, and I went, "Holy crap, I don't recognize my boy." That was pretty hard. But I can’t think of anything else that has been hard.

Gerald: How do your lives compare with others?

Amber: Our lives are not like everyone else. Our “normal” is different than a lot of people. We have a lot of therapy. I'm a lot busier than probably most moms.

Gerald: What are the joys that you've experienced?

Justin: Oh boy, do I love that.

Amber: There are just so many.

Justin: That kid makes me feel so good as a dad. It’s a joy you can't explain. For Christmas, Amber got me a little calendar with pictures that I have on my desk at work, and when you show people that, they just go, "He is just beautiful." I can't explain it, but they are just drawn to him, and that is the biggest joy I have, how he can do absolutely nothing yet he is the biggest spotlight around. People are drawn to him, and he just loves it. He loves it.

Amber: He's just sunshine.

Justin: He is so joyful.

Amber: He just has a presence. I don't know how to explain it exactly, he’s just amazing.

Justin: Yep, he is.

Amber: He just loves everybody and...it's hard to explain, it’s just love.

Justin: He makes you want to be happy.

Amber: You can't help it.

Justin: You want to bring him and he's just like, "Oh my gosh, he just makes me happy." You know, he just makes me happy.

Amber: I think, too, that you find a lot of joy in his accomplishments because you know that things don't come as easily to him as they do to typical children. You know that everything he does is harder, rolling over, sitting up, walking, talking. For every little milestone, you work so hard and he works so hard. You see him master something, and there’s this huge excitement for everybody. It’s a straight-up celebration in this house when anything new happens. He learns to clap, he learns to crawl, he learns to walk, it’s just amazing. If we ever go to school, the kids grab him and take him to show their friends what's going on because it’s so exciting. I think there's a lot of joy in that, in watching the things that he does well, because he's tough. Our daughter wrote an essay for school that we didn't know about until she was done, saying that he's her hero, and I think he's a tough little man. She talks about how getting him through what he needs to do, that probably most of us would just quit because it’s too hard, but he doesn't quit. I'm afraid to try and choose a guardian.

Gerald: What about extended family?

Amber: If something were to happen to us, I'm afraid that there would be fights over him.

Justin: Well, I think both of our families regard him as a special gift and just adore him, and they almost want that opportunity to just be with him in his presence, to hold him and to help teach him as well. He's been something that my family, my sisters, my little nieces and nephews have all just taken under their wings and have just been in awe that he has come to our family. And they are grateful for the opportunity that they have to be close to him.

Amber: One of our little nieces was watching him one day, and I went to pick him up, and she said, "Amber, everyone loves your baby more than any other baby, even strangers." And I thought that was really funny that at 11, she pointed that out because she notices how different he is. There are a lot of little babies in our family, and she noticed how people are drawn to him. I think that for our immediate family, something that we worried would divide us has actually brought us much closer and tighter together, and a lot of people say that it’s the blessing that you never knew you needed, or you never knew you wanted, and that’s exactly how it’s been for our family.

Gerald: You had some other family concerns.

Amber: We worried because our two kids are from Justin's previous marriage, and we worried some about bringing another kid together into that situation, knowing that these kids need our time and attention, too, and it’s hard having those two homes and places, especially with the health problems and all of the attention that he gets because of his Down syndrome. There couldn't have been a better kid for our family.

Gerald: What would you share with others who find themselves pregnant with a child with Down syndrome?

Amber: I think the first thing is that I would have 10 more just like him if I could. We would like to have another one. We don't have the genes for it, they say, but we may just have to buy one. Often families do adopt children specifically with Down syndrome, because as scary and awful as it is to begin with when you don't know anything, it’s just because you don't know. That’s all it is, you just don't know, and it’s okay to be scared, and it’s okay to be disappointed, and it’s okay to grieve the loss of the life and the kid that you thought you were going to have because your life looks different. But it’s better than you thought. It’s harder. Our life is not a normal life exactly by everyone’s standards. We have a lot of doctors, we have a lot of therapists, we have a lot of things. But, man, we'd do it 100 times over. We wish we could.

Justin: I agree whole-heartedly with that. What first comes to my head if somebody I knew were in our situation, or facing that situation, it would just bring a big smile to my face because I know the joy these children bring to our lives. I know every situation is different, but I think if we were to get pregnant again, I would hope for that. If it did happen, I would have the biggest smile on my face just because it is such a joy to have him. It is just pure joy.

Amber: I would agree with that. I was just thinking, when you asked about the joy, that Finneas brings out the best in people. That just brought that to mind. He is able to draw out the best. I'm sure at some point, he'll bring out the worst in some people, too, but you know, I really think they have a special talent for that.

Gerald: What a great time I had visiting with Amber and Justin, two wonderful people who chose not to abort Finneas, despite the recommendations of medical professionals, and who are seeing the positive impact Finneas had, and is having on them, their family and those around them.