

An Orange Socks Story – Terah and Brian: Down syndrome

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I was really excited to meet with Terah and Brian. They tried unsuccessfully for five years to have a child and were finally able to get pregnant through in vitro fertilization. They did not have prenatal genetic testing done. They were grateful to have a baby and were confident all would be well. They found out that Indy had Down syndrome when she was born, which, of course, was a surprise. Indy is now 10 months old, and I appreciated Terah and Brian's honesty and positivity as they talked about her life. They were right all along that all would be well.

Gerald: Terah, when did you find out that your daughter had issues?

Terah: About an hour after she was born.

Gerald: So, you did not know beforehand?

Terah: No. We had done in vitro fertilization to get Indy. We had tried to get pregnant for five years, and we did two rounds of in vitro, Indy came from our second round. She started out as a twin, and by the time I was at 11 weeks, we lost her twin. The pregnancy continued, and we didn't have any problems, it was a very normal pregnancy. We did not do any genetic screening. We thought about it, but we figured that we had done IVF, and that's a pretty fail-proof method. I thought that meant everything would be fine with our child. We had also decided that if there was anything wrong or were any issues, that we wouldn't choose abortion anyway, so we decided not to worry about the testing and just go through the pregnancy and see how the ultrasounds look.

Gerald: Okay, so Brian, what were your thoughts when you found out you had a child with Down syndrome?

Brian: A little scared. I think the unknown was the hard part. I hadn't been around a lot of families who had babies with Down syndrome or kids with Down syndrome. I didn't grow up in neighborhoods with any sort of physical or mental conditions like that, so I just didn't know what to expect. I think you have this vision of what your life's going to be like or your baby's life is going to be like and how everything plays out, and when you get a diagnosis like that, you start to question everything. Is it going to be like that or is it going to be something different? Is everything going to change? I was just surprised and stunned. Overall, it was just news that we kinda had to swallow and figure out.

Gerald: Terah, what were some of your thoughts when an hour after you gave birth, you had this child that was a surprise, a child with Down syndrome?

Terah: I took it a little harder than Brian; I had a really hard time. I kind of felt cheated a little bit, like we had waited so long for this baby, and we worked so hard to get this baby, and my thought was that we got a broken baby. I feel bad to even say that now because that is definitely not the case, but those were the thoughts that I had. It was really hard and really scary. I worked as an ER nurse at Primary Children's Hospital, and I had taken care of children with Down syndrome, so I was scared just because I had seen a lot of heart conditions and different things in the hospital, so I was really scared. I just thought that our new life was going to revolve around doctors and hospital visits and sickness and surgeries and scary things.

Gerald: Tell me, what have been some of the hardest things about caring for Indy?

Terah: Honestly, the hardest thing for me has been the emotional acceptance. The actual taking care of her really isn't different than any other baby. She has been fairly healthy. She did come home on oxygen, and

that was hard, but it was totally doable, not that hard. We've had several doctors' appointments and occupational physical therapy every week, but those things aren't very difficult and have just become part of our lives. It's no big deal to have therapy every week, it's an hour and it's fun. The hardest part for me was my emotional acceptance of just having a child with a disability, with Down syndrome, not because of the efforts I've had to put forth to take care of her.

Brian: With a child with a disability, you're going to have different activities and different habits and routines whether you have to budget in time for an hour every Wednesday or every other Wednesday. It just gets worked into a routine. I think scheduling wise, it's not that different. I mean, you are going to have a few more doctors' visits than you might not have had otherwise, and you might have a surgery that you otherwise wouldn't have, or we might have to help Indy learn something a little bit longer than we would have had to do. But overall, I don't think it has changed much, I think it's just turned into life.

Gerald: What's been the hardest thing for you, Brian?

Brian: I don't know. I think the first hour or two hours were trying to wrap my head around it, and then the first night, I said, "You know what, I'm not going to make a big deal about this." I can't think of things that have been particularly difficult for me.

Terah: Probably dealing with me.

Brian: Helping mom get through the difficult parts, because to be honest, after that first night, I accepted it. I said, "Look, if anybody can do this, it's us, and we can and we will," and I had that determination right off the bat. When something difficult did come up, instead of saying, "Oh, yeah, this is hard, I don't want to do this," and struggling through it, I thought, "Look, this is it, and I'm going to do it and I'm going to crush it and get it done." I don't think there have been a lot of things that have been really that difficult for me since then. She is 10 months old now, so I'm sure there is going to be stuff that is really, really hard for me to see, for me to go through emotionally or physically. But as of now, it's just been fun and been a good ride.

Gerald: Easier question, what have been the joys?

Brian: She is a cute little thing. For me, it has been nice when people have said that when you can't do things, or that she won't do things and then she does them, you get so much more achievement out of small accomplishments than you otherwise would have. Lots of times, they tell you that babies with Down syndrome can't do this and can't do that, and they are not going to eat well, and they are not going to be able to stand or sit or start talking. They don't expect these things to happen normally, and so Terah has been excellent working with Indy and giving her every opportunity and training so that when Indy does achieve something, it's like a success, proving the world wrong. That to me is joy, saying, "Look, we are doing this." That is my favorite part of the whole process.

Terah: Indy is doing it.

Gerald: What are your joys?

Terah: She is incredible. Every time I look at her, I just can't even handle the amount of love I have for her because she is just pure joy. Like Brian said, every achievement is so rewarding because we work harder for it, but also in the beginning, we didn't expect it. They tell you all these things, like breast-feeding was important to me, and they told me that babies with Down syndrome typically don't eat well so you might not be able to breastfeed, and if you do, it might be really hard. That is just an example of where our expectations were set so low because of what people told us to expect. Then what Indy did was totally different. She is an excellent nurser, and she eats amazingly well, and she's grown so well, and her development has been really not far behind a typical schedule. That is definitely not something that we expected, that is not what they told us. Like Brian said, every milestone she hits, every achievement is just so fulfilling and rewarding because she is doing it and we are doing it. It's amazing and has been just a really great journey.

Gerald: What has been her impact on your extended family?

Brian: Holy cow.

Gerald: Go ahead, Brian.

Brian: That to me has been the most amazing part, that makes it seem like this is meant to be, that Down syndrome can turn into something so awesome when it has a stigma of not being great. We've had some really cool experiences with our immediate families and our extended families where you can tell, just by being around her, they are changed people. They think differently, and they act differently. I think Indy wants our family to be better people, and I think she allows them to have a higher vision of what we are all doing in life. If that means they make better decisions for their own lives, or make different decisions on the relationships they have with each other and with other people. I just think those are just many of the ways that she's been able to impact by just existing, by just being around. People know that this is a part of our family.

Gerald: Do you have anything to add to that, Terah?

Terah: I would just say that in the short 10 months of her life, it has been incredible to see what's happened with our families. When she was a week old, she actually got a blessing in the hospital, and in her blessing, it said that she would create bonds in our family that otherwise couldn't exist just by being here. It has been incredible to see that happen. From the very beginning when she was just a week old, the bonds that already started to form in our families and the issues that were present on both sides of our families have seemed to dissolve so that they don't seem present anymore. It doesn't seem like there is any contention, there is just love, and that's what she has done for our families.

Gerald: That's great. If I were to come to you and say that I've had this diagnosis of a child with Down syndrome either in utero or shortly thereafter, and I'm new to this whole experience. Terah, what advice would you give me?

Terah: I would just say that your life is about to change for the better. I don't know how else to put it. From the beginning, I thought that this is the worst thing that has ever happened to me, not Indy, but just Down syndrome, that was my initial thought. I was devastated. Now I truly and honestly feel like this is the best thing that has ever happened to me. It has changed my heart and made me such a better person and so much more compassionate and loving and humble. I cannot think of one negative way that this has impacted me or my family, so I would just say keep your head up. I had a really hard time with acceptance, and it took me probably three months, and even still, I have days where I feel a little sad, not about Indy, but about Down syndrome. I think that is natural, and I think that it will get better, but I would just say to try to find the joy in it, because it is so joyful.

Gerald: Brian?

Brian: If there is something that somebody would have said to me, and if there's some sort of advice that I could project or things that I've learned, it's first, there is nothing to be scared of. You're going to have maybe more time commitments or financial resources dedicated to this, but those aren't the important things. When it comes to the important things, Down syndrome is a blessing. Down syndrome will help instead of hurt. Secondly, don't be conquered by it. Don't think of yourselves as someone who got diagnosed and now you're stuck with Down syndrome. You live your life, and you go get your life, and you do the things that you otherwise would have done. If you like camping, you go camping. If you like movies, you go to the movies. You bring Down syndrome into your life instead of your becoming the Down syndrome life. Don't be conquered, don't get discouraged, don't think that you can't do it because you can and you will.

Gerald: Wonderful. Thank you both.