An Orange Socks Story – Jennifer and James: 3 with Down Syndrome and One with Reye Syndrome

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I was excited to visit with Jennifer and James. My oldest daughter saw the family in the mall and was so impressed with them that she had to meet them and learn their story. Passing the information along to me, I wanted to meet them. Jennifer and James ended up with four biological children and six internationally adopted children, four of whom have special needs, one with Reye syndrome and three with Down syndrome. This family is such an inspiration. I am so glad I had the opportunity to meet them. I am inspired by them. All of their children are equally loved and wanted, and all are recognized as their children who needed to be part of the family. Jennifer, will you start by telling me the story of your family?

Jennifer: We have 10 children, four biological, six internationally adopted children. Our oldest is 20. Our youngest is two. She's kind of a caboose. We have an eight-year-old, and then the others are spread out between 13 and 20.

Gerald: And some of the children have disabilities?

Jennifer: We have four children with special needs. From when we first went over to adopt our daughter from Kazakhstan, everything looked great. Then we had to leave for the legal waiting period. During that time, she and the other children in the orphanage got chicken pox, and they gave them aspirin. So, she ended up with Reye syndrome and came home with severe liver problems and cognitive disabilities. Her diagnosis actually came a few years later. James was on a business trip, and I took her in with Kids on the Move for some testing. They did the testing and told me that she had severe autism. I remember just being crushed which surprised me because I am a special education teacher. It surprised me how crushed I was to get that diagnosis. I called my mother, and she said, "Don't tell James over the phone. Wait until he's home and can hold his baby and know that it’s going to be okay." So that's what I did. I went and picked him up that Friday night and took him to a restaurant, and told him what had been found on the tests and the assessments. It was very crushing. That being said, she is one that has never been limited by what other people tell her she's going to be limited by. Long story short, she's now a freshman in high school, and we had at one point been told that she would be able to graduate public education knowing her alphabet and knowing to count to 10. She is on the honor roll as a freshman. She's receiving IEP and 504 services, but she is amazing. She has a painting in her room that says, "She thought she could, so she did." That's been kind of her motto her whole life. As soon as I think we're going to hit a ceiling, she breaks through it. I just can't wait to see what else she does.

Gerald: Great story.

Jennifer: We had three biological children, and then had an experience where we very much knew that we had a daughter somewhere who we had to find, and so we brought her home. Then we had several miscarriages. We had five in total, some of them quite late in the pregnancies. Then we had our little miracle baby who wasn't supposed to make it, but he's here, and 13 and amazing. After a couple of years, I started getting that feeling again that it was time to adopt, it was time to add to our family. We began the process, and I remember when we were in the beginning stages, we had five children, and most countries will not allow you to adopt a typically developed child if you have that many children in your home. So, we knew we were looking for children who were on the waiting list and who probably had special needs. They asked us, "What are you open for? What disabilities are you willing to have your child have?" That was a difficult process, because I knew we had a child who was ours. I didn't know what disability they would or would not have. As we were going through the paper and looking at what some of these disabilities were because we had never heard of some of them, we realized we needed to check them all because we didn't know who our child was. So, we checked them all, and then it was just a few days later that I got the strong, strong feeling that it was time to go back to the internet and find our child. I pulled up the Rainbow Kids site, and immediately our son's picture popped up, and I recognized him. I knew it was him, and he had Trisomy 21, Down syndrome. That was a little bit of a shock to me. I said, "Oh, he has Down syndrome." But I knew without a doubt that he was our son, and I've always had a connection for people that had Down syndrome. I taught swimming in our high school during second period to the self-contained classroom. That was an ID unit, so it was mostly filled with children with Trisomy 21, and I loved working with those special people. That's how I ended up going into special education and becoming a special education teacher. We've said before, and I believe it, that third chromosome is the love chromosome. That's their gift. That's absolutely their gift. So, we proceeded with the adoption of our son Jacob, and just a few days before we went to go bring him home, when our bags were literally by the front door, we received a phone call that he had had a seizure and was unconscious, that we weren't allowed to come. The next day we received another call saying that he was awake, but that he was paralyzed completely on the left side. I remember our social worker saying, “You didn't sign up for this. You don't have to complete the adoption. This is not what you signed up for.” And I remember telling her, "I wouldn't leave any of my children if this happened to them. He's my son." For about a half a day there, James and I really did kind of wrestle with it. How is this going to affect the rest of our children to bring home a child that not only has Trisomy 21, but is also completely paralyzed on the left side? What is that going to mean as far as what we can do as a family? Really, at the end of that day, it came down to the fact that he's our son, and it doesn't matter. We had to wait a couple of weeks before we were allowed to travel, but then we went to get him, and during that time, he had healed quite a bit and had regained the use of a lot of his left side. He never really did regain the use of his left hand very much, but it was while we were there in country that we met his best friend Michael in the orphanage, and as soon as we came home, we knew that they were meant to be brothers. Michael had always taken care of Jacob in the orphanage and was like a big brother to him, so we needed to make it official. Just about two days after we got home with Jacob, I took him to the hospital for an MRI to find out what had happened. I remember I was holding him in the recovery room, and I got a call on my cell phone from the pediatrician who said, "This can't wait." The radiologist read it and immediately contacted the neurosurgeon with the news that Jacob had Moyamoya disease, which is a malformation of the vessels and veins in the brain. The episode that he had in China was a stroke. They immediately went in and did brain revascularization on one side of his brain, and he healed and did beautifully. After he had been home three years, we went in for another MRI and were told that things looked stable. He was going to need the brain revascularization surgery on the other side, but they wanted to wait until his veins were a little bit stronger. About nine months after that, he had another massive stroke. He was in intensive care for three days, and they did a craniectomy on him and everything else that they could do, but he passed away on December 15th, and there's not 10 minutes that I go without thinking about him. The interesting thing is that people make comments and ask us if we wished we hadn't brought him home, so we didn't have to go through this tragedy and this loss. Emphatically, I would do it a million times over, because the time that we got to have him in our home were the best years of our lives. I would go through the heartache and the pain of losing him over and over and over and over if it meant that I had that time with him again. We brought home Michael just a year after we brought home Jacob. He also has Trisomy 21. Then we started the adoption of our two sons from the Democratic Republic of Congo, and they were legally ours as of the summer of 2013, but the government and the DRC put a suspension on exit permits for internationally adopted children, and they were not allowed to leave the country until March of 2016. We worked with our government, the Department of State, and our senators, and finally we were able to get them home. Immediately, a week after that, we very much got the feeling that we had another little girl who was waiting for us. A series of events, miracles I'm going to say, led us to our daughter Lillian who was from the same orphanage as Jacob and Michael, and she, too, has Trisomy 21, and she just came home two weeks ago. So that's our family.

Gerald: That's awesome. So, James, what are your thoughts about all of this?

James: Well, in terms of thoughts, one of the things Jennifer and I talked about just the other day is that many people have a large set of friends who they do things with and really enjoy their time there, and I think that's wonderful. But for me, I can't wait to be around my kids. They're my best friends. They're amazing, and I can't stand being away from my wife. When I'm with my wife, I'm okay, but after that, I would much rather spend time with our kids than anybody, and that's all of our kids, every one of them. It's not even something like, "Oh, I kind of like being able to spend some time with them and they kind of connect," it's that every one of them has something that they bring into my life that I can't get anywhere else, different aspects of what they like and different aspects of what they do. I know we've been talking a little bit now, maybe some things that people would think to be disabilities really are abilities. I'm the one who gets choked up way to easy. They have abilities that I can't find any place else. Lillian has brought light into our house that I can't even begin to explain. It's not that there wasn't already tremendous light here, but she has a unique ability to do things that none of our other kids can. Each one of them has something special that they bring to our family, and it’s not just that they were without our family wherever they were, it’s that our family was without them. Our family was incomplete, and our being together is where our happiness comes.

Gerald: So, tell me, you had our biological children, and you added the adopted children who have various disabilities and special needs. What impact have they had on your biological children?

James: There are some things that might just seem obvious. If you look at our children with special needs, each one has gained things from their younger siblings that are maybe obvious. For example, my oldest son is a remarkable young man. We used to comment on the fact that he would get up in the night when his brother would wet the bed, and he would just get up, take care of the laundry, clean things up, shower his brother and put him back in bed without even bothering us which, for a teenage boy, is very unusual thing, right? There are these things of patience and kindness that they learn, and it has helped them to be better people. One of the things that's so big is that it has also helped them to be happier. Since Lillian's been home, we've been watching our kids, and just the joy she brings into their lives makes them happier. There are all the things they've learned in terms of patience and kindness, and maybe you'd call it almost semi-parenting skills and things like that. But they're also just so much happier, and each one of their siblings has brought them that.

Jennifer: It's like someone poured glue when she came in the house. Like I said, we were already a close family, but it’s like someone poured superglue on all of us, and wherever Lillian is, that's where I will find everyone else. They're with her. One thing I would add, it’s very interesting when any of our children talk about their future families. All of them talk about when they adopt, and most of them will verbalize that they hope they have a child with special needs, particularly Down syndrome, and several of them have said that if they are not given a child biologically who has Trisomy 21, that they plan to adopt a child with Trisomy 21. We actually have a daughter who's afraid that she'll never have a child who has Down syndrome. She's scared that she might not. It just brings her so much joy to be around her siblings.

Gerald: Jennifer, what impact has your family, your adopted kids especially, had on your extended family?

Jennifer: I was talking with my mother about this just recently, and she said that a woman at church had come up to her who was very sad, very distraught, because her daughter had just found out that the child that she's carrying has Down syndrome, and my mother said to her, "Oh, please don't be worried, don't be scared, don't be concerned. It's going to be one of the biggest blessings that will come into your life." It's now been two-and-a-half years since that child was born, and with Lillian coming home, they were talking about this again. She said, "You were right. You were so right!" I've seen that with our extended family in how comfortable they are with people with special needs. Because of our children, they are much more comfortable in being around other people with special needs in their communities, just the acceptance. They all have a very special connection with all of our children, but particularly our ones with Down syndrome. Actually, my brother was the one who said to me after Jacob's funeral, "I think that their chromosome is the love chromosome." It's been fun to see that they've not only impacted us in our immediate family, but in our extended family and our community. What I've realized as a mother of 10 is that every child has unique and special needs. They may not have a diagnosis, but every child has a set of unique and special needs. One thing that has been interesting as a parent is to realize the relief with my children with Trisomy 21 because the stress of having to succeed is gone. "You have to get these grades, you have to do this certain activity," that stress is gone, and it's just all about loving them. It's actually almost easier for me to parent them because that outside stress of expectations is gone, and all I can do is love them and make their lives happier and better today, and take away that outside expectation.

Gerald: James, I'm going to start with you with this question, then Jennifer you can follow because I'm going to give you the last word. If I came to you seeking advice because I had received a diagnosis, either in utero or after that I had a child with a disability and I was devastated by the news, what advice would you give me?

James: The advice that I would give you is that your child will bring you more joy than anything you can imagine, even if you have to suffer through pain, because your child may have received a diagnosis that could be one that would shorten their life. I would tell you that the months that you will have will far outweigh any of the tremendous pain you will experience after their loss, and I will tell you that the months and years and hopefully decades that you will have with them will vastly outweigh anything that you could experience without them. All of our children are the source of our joy, first and foremost. I experienced with Jacob something that is painful and difficult, and I wish I could find meaning in it. The closest thing that I can find to meaning is that I have experienced not having my child, having my child and not having my child again. So, with a voice of knowledge, I can tell you that having your child will be the greatest blessing you will ever know, and that still holds true even if you have to lose that child someday.

Gerald: Jennifer?

Jennifer: I firmly believe that children are placed in families where the parents are given a special ability to take care of that child, and that there's a reason that child went to that family. I firmly believe that loving parents who want the best for their children will be able to rise to any challenge that they will have in caring for that child with special needs, and that they will know better than anyone how to love them, and that love will be reciprocated ten-fold.

Gerald: Thank you, you guys are awesome.