An Orange Socks Story – Adrianne and Jason: Tetra-Amelia syndrome

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I'm so happy I had the chance to meet with Adrianne and Jason and their daughter Maria, who has Tetra Amelia Syndrome. Adrianne and Jason adopted Maria from the Philippines, and she has become a wonderful addition to their family.

Gerald: Adrianne, tell me your story. You have a unique story in that you adopted a child from the Philippines. Do you want to tell me about that?

Adrianne: We have two biological daughters, and I had a really hard pregnancy with my second, so we decided not to have any more kids that way, but we knew our family wasn't complete. First we adopted our son Joshua, who is six now, and two years ago, we again decided our family wasn't complete and wanted to adopt again. This time we started looking at children who were waiting to be adopted from what is called the special home finding list. These are kids who are older, who have special needs or are part of sibling groups. One of the first emails we got included a picture of our daughter Maria, and we had actually heard about her before we saw her picture. I remember thinking, "Wow, that would be really hard to parent a kid like that," and we just kind of brushed right over it. Then the next day, we saw her picture again, and we thought, "Wow, she has the most beautiful smile," and she was so adorable that we just knew we needed to find more out about her condition and more about her, and then we decided to make her a part of our family.

Gerald: What is her condition?

Adrianne: The technical name is Tetra Amelia, missing all four limbs.

Gerald: What were your thoughts, Jason, at that time?

Jason: I think back on it, and I swear I remember the conversation going, "Well, what do you think?" I said, "I don't know, why don't we?" but I don't know if that is accurate. I didn't really have a lot of thoughts against it, but we had questions because we didn't know much about it. s I remember when we decided to look into it, we went to the internet and searched for her condition and people with her condition. One of the first ones we found is now a motivational speaker, Nick Voycheck. It's just mind-blowing how motivational he is. Then we found some others, and it seemed like almost every person we could find who had this Tetra Amelia was for the most part a very productive member of society, living a very good life. That really brought us a lot of comfort as to what kind of life our daughter could have.

Gerald: How long ago did you adopt Maria?

Adrianne: She has been home with us for almost a year and a half.

Gerald: Okay, so what have been some of the hardest things you've had to deal with?

Adrianne: It was a year before we even brought her home, which gave us a lot of time to prepare, so we were able to go online and find other families with kids with similar conditions and ask them questions, and find resources in our area. I guess for us that was the hardest part, just finding all our resources. This was our first child with special needs, and we didn't really know how that all worked and what resources were out there, so it took a little bit of research on our part.

Gerald: Did you have a tough part for you from your perspective Jason?

Jason: My perspective has always been, “How am I going to pay for everything?” Adoption in itself is expensive, and then to adopt a child with special needs started my gears turning about what this is going to cost us. I had some reservations about that, but I think there are great resources out there. I mean, we take our daughter to Shriner’s hospital for therapy, and through the process, we found the school district had programs, and it’s been really good.

Gerald: Maybe an easier question would be what have been some of the joys?

Jason: Watching her smile and watching her laugh. When we first brought her home, she was just over two years old and had spent most of her time in those two years in a little cottage with infants, so it almost feels like we got to watch her grow up. She didn’t know how to play or interact, so we’ve watched her grow and find ways to interact with us. Her laugh is just adorable. We found out what she enjoys; she likes being in swings, and she likes movement. Her reaction when we first got her a motorized wheelchair was, “I’m making myself move,” and that was just incredible. Within the first two weeks of being home, Adrianne had found a way to get some elastic and strap a marker to her arm. We put a piece of paper on a clipboard, and she started moving her arm across the paper. Just to see her make that connection, that,”Hey, I’m doing this” is an awesome feeling.

Gerald: That’s wonderful. Adrianne, would you like to add some of your joys?

Adrianne: I’d say a lot of the same, and seeing her overcoming things that I didn’t think were possible. We put limits on her abilities, and she just turns around and does things we don’t think that she is capable of doing. She surprises us every day with things that she learns how to do. She is just so smart, and she is so willing to try everything. She can’t even sit up on her own right now, and when we first brought her home, she couldn’t even lift her head up. It has taken a long time to develop all the core muscles and everything she needs. When I put her at the top of the stairs just to see what she would do, she started wiggling, and she ended up going all the way down the stairs, and she kept her balance. It was amazing.

Gerald: Wow, that is interesting. What impact has she had on your immediate family?

Adrianne: I know she has helped us and especially our kids look at people with disabilities differently. A lot of times, you think that people who are missing limbs or have other disabilities are going to be sad and have a miserable life, but she has taught us that you can have just as much enjoyment in life no matter how you are born. It has helped us all to look at people differently, and I’ve seen our kids be more open now to being friends with kids who are different and be a lot more accepting.

Gerald: How about your extended family, Jason?

Jason: They’ve been real accepting and just real loving of her, really supporting us in different ways. Technology is great because my parents live north of Seattle, and technology is great with Facetime or Skype or whatever program you want you use. They can get on and talk to her, and they love talking to Maria and seeing her. It also helped the first time we actually went up to meet my parents. She was able to recognize them, so it was kind of nice. We’ve had a lot of really good experiences with our extended family.

Adrianne: I think they had some reservations in the beginning; I know my family did. They were concerned for us and how we were going to deal with it.

Gerald: So more concern with you.

Adrianne: Yeah, more for us. My parents haven’t been around a lot of kids with disabilities in their lives; they really didn’t have a clue what it was going to be like. However, everyone who meets Maria just falls in love with her. They just can’t help it because she is so loving, and she just lights up the room with her smile.

Gerald: So English is her second language and her primary language was…?

Jason: Pilipino also known as Tagalic, which would have been the majority language spoken in the orphanage. There was some English mixed in with some of the helpers as they had volunteers come through, and also some of the founders speak English, I believe.

Adrianne: Yeah.

Jason: Also some of the board members and that chair…

Adrianne: But she was getting primarily Tagalic.

Jason: Right.

Adrianne: Since she was only with the infants, her language level wasn't very high to begin with. She did know Tagalic when we got her, and she had to learn English, so she is a bit behind in the speech area.

Gerald: How challenging was that for you, to adopt a child who may not understand what you are saying?

Adrianne: Well, thankfully, Jason served a mission in the Philippines and knows Tagalic.

Gerald: You did?

Jason: I did.

Gerald: What a blessing for you and for her, where you can speak and actually transition her into English.

Jason: It it did help quite a bit, as well as with our son because he was also from the Philippines. It has been good, because even though they knew a little bit of English, I was able to use real basic Tagalic and help that transition.

Adrianne: He was also able to teach me some.

Gerald Oh, that's terrific!

Adrienne: Along with some Rosetta Stone, so I knew the basics.

Gerald: That's fun, that's great If I came to you and told you that I had found out that I had a child with Maria's condition either in utero or in after, what advice would you give me?

Adrianne: I would say to relax, it's going to be okay. There are so many resources and different groups. Through social media, there are all sorts of different limb deficiencies or different conditions, and you just take it one step at a time, because they are going to start as a baby, doing the same things that all babies do. Then as they grow, you kind of grow with them, and you know learn how to do different things in a different way. They are going to be doing the same things that your others kids, or if you haven't had kids yet, they do all the same kinds of things, but you just have to teach them how to do it in just a little different way. For the most part, they are really smart kids, and they figure out how to do things on their own. I'll try to show Maria how to do something, and she kind of shakes her head like she doesn't want to do it that wa,y and she'll find her own way to do it.

Gerald:That's interesting. Jason, do you have anything to add?

Jason: Just that like any other kids, these kids just want to be loved. All kids need a family. They want to be loved, and if you love them, they are going to love you back.

Adrianne: And they will thrive.

Gerald: Wonderful.

Adrianne: And do amazing things.

Jason: They really don’t know any different when they are born that way; we look at it as a deficiency because we were born and raised with arms and legs, and we learned how to everything just like every other kid, but they are born that way and don’t know any different, so they grow up that way and learn how to adapt.

Gerald: Hm, that’s great, thank you.