

An Orange Socks Story: Connie- Cerebral Palsy, Cognitive impairment, Seizures
Interview by: Gerald Nebeker, President of Orange Socks

Gerald: Connie, thank you so much for taking the time to meet with me to talk about your daughter Farah, who is now 41 years of age. her diagnoses are Cerebral Palsy and a cognitive impairment with a seizure disorder. She uses a wheelchair. When did you find out that Farah had these diagnoses?

Connie: I saw them much earlier than anyone else did as a mother, but she was officially diagnosed at about six months.

Gerald: Okay, and what did you notice?

Connie: Her seizures.

Gerald: Oh, so even as an infant she was having seizures?

Connie: Yes, she was having seizures.

Gerald: Over the 41 years that you've known Farah, what have been some of the challenges that you and your family have faced?

Connie: Well, I think emotionally at the very beginning, you have the challenge that you almost go through a grieving process because the child is not what you wanted her to be and the life that you wanted her to have. At first, you don't want to accept it, and then you finally do accept it and then you see that it brought us probably a lot more blessings than anything else. I think it has given us depth and wisdom to our family that many people never achieve in this life because you really see what's important very quickly.

Gerald: Awesome.

Connie: I was very young when I had her.

Gerald: I'll have you expand upon that in just a second, but in terms of the care and daily work with her, tell me about some of the care that she requires.

Connie: Farah is what we call "total care." She's like an infant. She depends on us for everything. We have to bathe her and feed her. She was put on a feeding tube about two years ago, and up until that point, we would prepare her food and feed her. You have to worry about her water intake, whether she is hot or cold, just everything. You have to become aware of her needs. She cannot talk; she's not vocal, so you have to learn how to pick up signals from her.

Gerald: Did anyone ever advise you to maybe place her in institutional care when she was growing up?

Connie: Oh, yes, of course, probably every doctor that we came in contact with before she was five years old. After about five years old, they stopped suggesting it, but they felt that for our family to be able to experience life as we should, we should probably institutionalize her, but we couldn't; she's our daughter and our little angel, and I would never put her under someone else's' care.

Gerald: Awesome. You started to mention some of the blessings, but would you mind just expanding on that a little bit and talking about the joys of having Farah in your family?

Connie: There are so many simple joys of having Farah. Just a smile fills your heart because it's such an innocent smile. You learn to appreciate all kinds of little things, and I think it has drawn our family a lot closer. It has given us empathy. We are very much aware of differences, and we are able to accept them. I think that my children are much kinder people, a lot more forgiving, and it's a joy for me to watch them interact with other people in our community that are handicapped in other ways.

Gerald: What was her impact on your extended family or your friends when she was born? How did your parents or your husband's parents deal with "Oh, my goodness, now we have a child with multiple disabilities"?

Connie: They were such a great support to us. It's quite funny to see the impact on my father. He was an old farmer, and he was very gruff and rough. Farah brought out the very best in him; he was darling with her. He would come over when we lived by them and every morning take her for a ride in his wheelbarrow, and it brought our family closer together. My other siblings and their children and everybody knows what Farah is doing, and everybody follows her on Facebook. They are all interested, and no matter what's happened to the people as they've gone their different ways, they all check in on Farah. They don't check in for anyone else, but they all know what Farah is doing, so Farah has drawn our family and extended family as well together. I don't think anything else could have.

Gerald: I'm just curious, if I came to you just having found out that my infant was just diagnosed with Cerebral Palsy, and it was apparent that she had a cognitive impairment and seizure disorder, what advice would you give me?

Connie: I would say number one to look at this human being as truly one of the biggest and best accomplishments you will make in your life. I think that you will grow more by taking care of this little child in ways that there's no other way that you could grow, that this child will bring so much happiness into your life. It's funny, because I have happened to know three or four people who have had children with disabilities who have actually taken care of Farah. That is actually unusual. When they were younger, they took care of Farah, and because they've taken care of her,

everyone looked at that child very differently. There wasn't any hesitation at all for them to accept that child into their life because they could see how Farah had blessed ours. When I'd call them to ask a little bit about what was going on in their life, they would just say, "We knew that we could do this because your family has done it so well, and because we can see the light and the brightness that she brings into our home." They didn't even have a decision to make; they knew it was going to be a great opportunity for them and a wonderful possibility.

Gerald: Any last thoughts that you want to share?

Connie: When I first found out about Farah, I have to tell you that it was probably one of the darkest days of my life. I cried, and it was so sad, but now that I look back on it, it probably was the best day. I wouldn't trade it for anything. I wouldn't trade her for anything in the world. Sometimes you do wish and you wonder if she had been normal, how her life would have turned out, but when you see all the ways that she's changed us for the better, I don't think that we could have done this without her. I see the people who have been affected by her. We had a birthday party for her when she was 40. There are lots of times I wonder why she is still on the earth when she's suffering. Perhaps it's because I haven't learned everything that I should from her. Then I realized that she's not just here for me, she's here for our community. We had 300 people show up in the rain to commemorate that birthday, coming together with the community and friends to tell us stories of how she has influenced their lives for good, so it was a marvelous experience, something that we weren't expecting.

Gerald: What a great blessing. Connie, thank you for taking the time to meet with me for this Orange Socks interview. I'm honored and just thrilled to learn about Farrah and your life with her.

Connie: Of course. I appreciate it.