An Orange Socks Story: Ann-Spastic Quadriplegic Cerebral Palsy

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: Welcome to the Orange Socks Podcast, where we are inspiring life despite a diagnosis. I'm your host, Dr. Gerald Nebeker. In this episode, I speak with Ann about her 41-year-old identical twin daughters, Kaye and Karen, who have spastic quadriplegic cerebral palsy. Sadly, Kaye passed away two months ago, but I had the privilege of meeting Karen. I am inspired by the strength of Ann and her commitment to keep Kaye and Karen at home, rather than following her doctor's advice and institutionalizing them as infants.

Gerald: Karen, thank you so much for taking the time to meet with me for an Orange Socks interview to talk about your daughter, Karen, who has spastic quadriplegic cerebral palsy. I appreciate it.

Ann: Thank you.

Gerald: When did you find out that Karen had this diagnosis?

Ann: When they were about three months old, they finally labeled it, but we knew that there was something wrong within 8-12 hours after they were born. She had a twin, we just lost her on October 27th of this year, so when I say "they," that's who I mean. They were both born via natural birth. Karen weighed 7.5 pounds, Kaye weighed 6.12 pounds. They were just beautiful. They were the talk of the hospital that night. When my husband was there, we were feeding them, and they acted like they were gagging on the milk, so we called the nurse in who said, "Let us take them, and we'll watch them, and then we will bring them back to you in the morning after we've observed them throughout the night." We didn't realize at that time that they were probably having seizures as neither one of us had ever seen a seizure. Later on, during that night, an RN who had come from the NICU into the regular baby nursery was looking at Karen and Kaye, and Karen had a seizure while she was standing there. She immediately called the doctor on call, and they moved the girls into an ICU nursery to monitor them. It was the next morning when I knew that there was something wrong.

Gerald: With both of them?

Ann: With both of them.

Gerald: Okay, were they identical twins?

Ann: Yes, they were.

Gerald: When did they actually get the definitive diagnosis?

Ann: We had them home for two weeks and would take them back periodically about once a month. It wasn't until then that they basically labeled it as spastic quadriplegic cerebral palsy.

Gerald: What were your thoughts when you got that diagnosis?

Ann: Their doctor came in and said that they weren't going to amount to anything, and that we should put them in a home and forget we ever had them. I literally came unglued and told him that the Lord had given me these two babies and that they were my responsibility, and that I was not going to put them away, that they were mine and I was going to do whatever I had to do to take care of them.

Gerald: 41 years later.

Ann: 41 years later.

Gerald: What have been some of the challenges that you've had over the last 41 years with twins with this diagnosis?

Ann: Keeping them well. Little Kaye was always my respiratory one. It seemed like she contracted anything that anybody brought through the door, so we had to make sure that we put signs up saying, "If you're sick, please do not come in." We monitored things pretty closely. Then there was their physical therapy, as they grew, whatever their little bodies needed. We would assess the situation and then decide whether it was for their benefit or ours, and then we would go ahead and do whatever we needed to do for them. As one example, little Kaye breathed and swallowed at the same time, and so she was always aspirating when she was eating. I would send their food to school and things like that, but they were always saying that it was so hard to feed her, so there was a year that I had to go there every day and feed her at school so that she could eat. There was a child who we knew and had seen who was so frail and fragile, and then the next time we saw her about three or four years later, she was a fine, healthy little girl. I asked her parents what they had done, and they said they had put a feeding tube in her, so in April, I took Kaye to a doctor who was a Gastroenterologist. He said that putting a feeding tube in her was not a big deal, he did 30 of them a month. It took me from April clear to October to decide that it was for her benefit and not mine. After we had the feeding tube put in, she just thrived.

Gerald: Any different challenges with Karen?

Ann: She loved food and she ate very well until probably the last seven years, and then she decided that she wasn't going to eat anymore. That's when I said that we'd put a feeding tube in, so then they were both fed through a tube. She had the ability to swallow and was able to take on that challenge, and since she loved food, it wasn't an issue.

Gerald: Ann, tell me about the passing of Kaye and how that has impacted you. She lived 41 years, and now that she is gone, what effect has that had on you and your family and Karen?

Ann: At first, they weren't supposed to live a year, they weren't supposed to live until age three, they weren't supposed to be five, then they weren't supposed to live to be eight, and finally I lost it with the doctor one time. I said, "Look, they are going to be here as long as God wants them to be here, so I don't want anybody telling me they aren't going to make it through this because I am going to fight tooth and nail for their lives here on this earth, and if God wants them, He's going to have to do something drastic." I've always felt that. With little Kaye, one morning I went to pick her up to brush her teeth and give her a drink, and her little arm broke. We had to take her to the Emergency Room, and they would not touch her because her little bones were so fragile and porous. Because they don't walk and they don't weight-bear, their little bones are that way, so she ended up with a blood clot that came from the arm into the lungs and that is what finally took her. It has cut my work in half. We miss her so much. At first, there was guilt, but it was something that I had done every day, three or four times a day, so the guilt didn't stay there very long because I knew that if it hadn't been me, it could have been somebody else. I was so grateful that it had happened to me and not to a trainer, because I don't know if a trainer could have gotten over that guilt of, "Look what I did to her." With me, I knew I knew that for it to have happened, it had to be out of my control, because it was something that I had done every day. I knew that our Heavenly Father had a hand in it, because everything that had taken place from the time it happened to the time she passed away was just like it had followed a script. Karen still misses her. I think she misses the conversation, they would sit here and talk back and forth a lot, and I think she misses her in that aspect but I haven't noticed a big change in Karen. I'm able to take her out by myself, so that's been beneficial for her whereas before I couldn't really do both of them. I would always have to have somebody with me. For Thanksgiving, I was able to take Karen and drive to California to spend the week with my son and his family. We came home and found out that she loves to travel, and she loves hotels, and she's a very great traveling companion. It has been an eye-opener.

Gerald: So, what have been some of the joys?

Ann: They are always happy. It didn't matter how bad your day was going because they were always being happy, and they made you happy. They brightened the room when you walked in, and they made your day. They were always happy to see you; just the smallest things made them happy. It just made you want to be around them.

Gerald: Tell me about the impact that Karen and Kaye have had on the rest of your family or the rest of your children or your immediate family.

Ann: We only had an older daughter at the time who was three years older than the girls. During those first years with the girls, it seemed like we faced a lot of things.

They had pneumonia, they caught every childhood disease, anything that came around. My parents basically raised my oldest daughter for a while. I just couldn't give her the attention that she needed, and she loved being with grandma and grandpa. My parents were right there and my husband's parents. My husband had another view at the time, he kept wondering what he had done to have children that were like these girls. I am LDS and he was Catholic, so he didn't look at the situation from my point of view or from the way I was raised. I felt they were a blessing, and while he loved them dearly and did anything he possibly could do for them, he didn't realize the blessing that they were to him until later on in life. He was always there for them and always made sure that they had what they needed. His job took him out of town a lot, so he was not around a whole lot through their growing up. My mother helped me out a lot. I had a little sister who came in and babysat for me and took care of them for me. She was awesome. Family members supported us, and they loved them and thought they were a riot. They all didn't quite know how to handle them or anything, but they were always very supportive of everything that was needed.

Gerald: If I were to come to you seeking advice that I just found out that I had a child with a similar condition, what advice would you give me?

Ann: I would probably tell you right off to contact first people with disabilities, the state with disabilities, because you're going to need help down the road. When they are little, you can transport them and do things with them, and you don't really need a lot of outside help. but as they get older, that's when they need wheelchairs. Then they grow out of wheelchairs and they don't walk. They do nothing for themselves; they need total care. You need to look at your home and realize that it is going to be fine for a while, but it's not going to last. As the years went on, there were different things that we had to do to accommodate the situation. I think my first advice would be to contact the state and let them know what you've got, and get on their waiting list so that you can get support. You just can't do it by yourself. We have so appreciated the help that we have received from the state. We have been able to keep them in our home and have been able to have them with us through their whole lives. If we had not had that help, who knows what we might not have been able to do.

Gerald: Interesting. Any final thoughts?

Ann: Just the blessings that we have been blessed with over the years, the knowledge of what they have given me and what they have taught me, the unconditional love and the love that you can give others. By having them, you have more compassion and more acceptance of people who don't walk like me or talk like me. I've truly been blessed with them and because of them.

Gerald: As I was picking up my recording equipment, I talked with Ann about all the work time and sacrifice that she has done over the last 41 years of providing total care for Kaye and Karen, and I asked if it was worth it. Without hesitation, she said "Absolutely," and indicated that the blessings far outweighed the efforts.

Gerald: Thanks for listening to this episode. Orange Socks is an initiative of Rise Incorporated, a non-profit organization dedicated to supporting and advocating for people with disabilities. Follow Orange Socks on Facebook and Instagram, and visit our website at orangesocks.org for more stories, and to find national and local resources to help parents of children with disabilities.