

An Orange Socks Story - Ann: Ataxic Cerebral Palsy and seizure disorder

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: It was an honor for me to meet with Ann for an Orange Socks interview. I have known her for many years; she is one of my heroes/ Ann has been a tireless advocate, organizing a group of moms to create a post-high school program for their children that did not exist previously in her state. Her daughter Chrissy had Ataxic Cerebral Palsy with a seizure disorder. Chrissy lived 33 years and passed away 11 years ago.

Gerald: Ann, thank you for meeting with me. I appreciate it. When did you find out that Chrissy had some issues?

Ann: I knew that she was a little slower, but all children are different, and I didn't pay much attention to it until this fellow came to my home to take her picture. We were a military family; my husband flies, and he was gone that day. This fellow came to take her picture, and he said, "Why can't she hold a book? Why can't she put her arm up to her face like I want her to do?" I said, "She can't do that," and he said, "She can't do that? All babies at that age can do it." She was 10 months old, and I said okay, and I didn't think much about it. Then I started worrying about it. My bishop was a pediatrician at the army hospital where I would go, and so when John came home, I said, "John, I want you to call Bishop Killiup and ask him when he goes to the clinic, would he see Chrissy for her one-year checkup early." When John called him, he said, "I've been noticing her at church. I'm glad you called." That made me think that something was wrong. When we went in, John was gone again, and I was there alone through the interview with our doctors. After we did all the tests on Chrissy, he said, "I want you to come in tomorrow, and we'll give you the results." I was alone again because John was gone for two or three days, and the doctor told me then that Chrissy has a disability, but we do not know how severe it is. I wasn't real concerned about it, but I called my mother and said, "Mom, the doctors say that Chrissy has a disability." She said, "Now don't you worry about it. She's a little easy going, and that's all that's wrong with her." I didn't worry too much about it, but that's the first thing that happened, and then things came later.

Gerald: When were they able to diagnose what Chrissy's issues were and what were they?

Ann: She was diagnosed with different things, but the final results were confirmed when we moved to Tacoma, Washington. A doctor up there in the hospital said that this is what's wrong with Chrissy, and it was ataxia cerebral palsy with a seizure disorder.

Gerald: What were your thoughts around that time when you got that diagnosis or during the ensuing time after you thought that something was wrong and then had it confirmed with the diagnosis -- what were you thinking?

Ann: The whole time she was such a beautiful baby and a cute little girl, said a doctor to me. We lived in Illinois at the time because we were a military family. I put her in a school there

where they told me that they thought Chrissy was having seizures. I said that I hadn't seen any yet, and they said they wanted me to get a doctor. So we went to Washington Hospital in St. Louis, Missouri. That doctor was the one who gave me the best thing in my whole life when he said to me, "I want you to love this little girl. She's beautiful, so I want you to take her home and love her. She's going to bring joy to your life as she grows. She's going to be harder to take care of, but your body will adapt to it; you will know exactly what to do for her. Just love her and keep her home." Later on, I wanted to take her to another doctor to get more results of what I could do for her. That doctor said, "I think you need to have a life with your husband. Put your daughter in a state school and leave her there, and you and your husband enjoy your life together." I said, "I don't think I will come back to you again, and I am not going to recommend you to anyone else. That is an awful thing to say, but I told him that I wasn't going to do that; I was going to do what I've been doing, and I'm going to love her and let her bring joy to my life.

Gerald: And you did.

Ann: I did.

Gerald: She passed away when she was how old?

Ann: Thirty-three.

Gerald: So she was 33 years of age. You did that for 33 years. You were her advocate.

Ann: Her advocate.

Gerald: What was the hard part with your life with Chrissy at home for 33 years?

Ann: I cried a lot because I didn't know what to do next. I'm a spiritual person, and I think she's the one who brought more spirit into my life. I got on my hands and knees a lot and prayed to our Heavenly Father to help me to know what I needed to do next. I think the hard part was taking her to things and having everybody look at me and wonder what I'm going to do and what I'm going to do next. She was part of our family and part of our life, and she's going to be with me wherever I go. I think the hardest part was when a teacher said to me, "Ann, what are you going to do when your little girl's not going to have a program because you kept her home?" I said, "She's not going to have a program?" "No, you kept her home, so she won't have a program." I didn't know that, so I started looking on my own at different programs, and I found out by going to these different programs that she wouldn't have one. That's when I came home and wondered "What do I do? I'm just a mom!" I got a hot pink paper out. I didn't have a computer, and I didn't have a cell phone at that time, and I sat here at the table and wrote a note: Dear Parent: What are you going to do when your child is too old and he's not going to have a program? What are you going to do, Parent, when your child doesn't have a place to live because you kept her home? What are you going to do about this, what are you going to do about that?" I said, "Come to a meeting at my house, and we'll talk about it." I rolled up the paper and put a ribbon on it, then put it in everybody's fruit bag at Chrissy's school and another

school. I got all these phone calls from people saying that they wanted to come to this meeting, and I thought, oh, boy, now I've got to plan a meeting! That was the hardest part.

Gerald: Ann did her research and spoke with local and state officials who gave her guidance on what to do to get funding to create a program, and more importantly, she got a group of moms together.

Ann: I found out that was the hardest thing I've ever done, pulling something together like this, because now we're going to lobby. I had never lobbied before, and I didn't know what I was doing. Then I joined the legislative coalition and went to the legislative board. I still don't know what I'm doing, but I'm doing it. They laughed at me, and that was hard, when they said, "You're never going to get that because your child is too severely disabled. You're not going to get it," and they laughed. That's when I said to myself, "I'll get it. I'm going to do it, and I'll get it." I was determined; the big word was determination. I will be determined to do this for my child, and she's going to have what everyone else has got; that was the big thing.

Gerald: And you were able to accomplish that.

Ann: I did.

Gerald: And you were able to get the funding?

Ann: It was only for three people at first.

Gerald: Then it expanded from there. You also had to physically care for Chrissy as she was in a wheelchair and required total care, so for 33 years, you provided that. Maybe an easier question to answer in some ways is what were the joys of having Chrissy?

Ann: She brought so much love to our family. We sang a lot in our home, and she was brightened up by the music. Not only that, the girls in our church did a program for her where I'd put her in the bean bag, and they'd come in twos and read her a story. They would sing, put a little tape on and play music and sing, and then another girl would come over and play the piano for her. It brought everybody in around us, so our home was full of life even with her. It's just a lot of joy in our neighborhood with the kids. We had a golf cart which was Chrissy's Caddy, so we'd drive around in the Caddy, and all the kids would jump on. She brought a lot of life to the ward.

Gerald: What was her impact on your family, her siblings, friends, neighbors and extended family?

Ann: They all just loved her. When she was here at home, she was included in everything. We took her everywhere; we took her on trips.

Gerald: You told me a story several years ago that I've always remembered about how your daughters used to use Chrissy to screen prospective dates or suitors who were interested in them. Do you remember that story?

Ann: If they came in and she smiled at them, they would date them.

Gerald: So Chrissy was the screener for the boys who were dating your daughters. I think that's cool.

Ann: If she looked at them kind of weird, then they didn't really want to go out with them again.

Gerald: That's a funny story. If I came to you knowing that I had a child with a similar diagnosis but I was new to this, and I just got this diagnosis and were to ask you for advice, what advice would you give me?

Ann: I think you would be hurting and wouldn't know what to do, and I think I'd probably say to you to love that child and give it a try. Don't let anything spoil you; just do everything you can. Every child is different and every disability is different. Some are harder than others. Mine was hard in a different way than some of my other friends, and I would say to never, never, never give up.

Gerald: Very good. Any final words? Was it worth it?

Ann: Yes, I have no regrets, none. Since I've lobbied and done what I've done, I've had people come to me and watch me. They just couldn't believe all the things that I did, and I couldn't have done it without my Heavenly Father.

Gerald: Thank you.