

An Orange Socks Story – Christine: Autism

Interviewed by: Gerald Nebeker, President of Orange Socks

Welcome to the Orange Socks Podcast where we are inspiring life, despite a diagnosis. I'm your host, Dr. Gerald Nebeker. I appreciate Christine sitting down with me for an Orange Socks interview. I enjoyed learning about her daughter, Skylynn, and Christine's experiences. Not long after she received the diagnosis that her daughter had autism, Christine received notice from her insurance company that they were denying coverage because Skylynn had autism. Not one to take that news sitting down, Christine became politically active to right this wrong, which led to other great things for her, and the state and the community she lives in. I'll let her tell her story.

Christine: My oldest daughter, my first child, Skylynn, was first diagnosed with autism around the age of two. She always showed symptoms of something being different. She would cry when I would sing, and she missed pointing and clapping. I was told constantly that, "Oh, I'm just a first-time mom. I don't know. She's not behind. I don't know what I'm talking about." It was when she was just under two that we finally had a developmental pediatrician look at her and say, "Yes, she has autism." I'll back up and say that it's pretty scary and devastating when you find out your kid has autism because you just don't know what the future holds. Everyone has this idea in their life that my kid is going to go to elementary school and then junior high, and then they're going to go to high school, and it's going to be great and we're going to be best friends. We might not be realistic in our ideas, but, of course, that's what we think. They're going to get married, and we just have an idea of how our life is going to pan out. The minute we are told that diagnosis, we don't know how our life is going to pan out, we don't know what changes there are going to be. We don't know how we can help our child or how we can't, or how high-functioning they'll be. You're just thrown into this situation where you aren't really sure what's happening. As I was sorting all of this out in my head, I received a letter from my insurance company denying my well-child visit where my doctor had recommended I go to a developmental pediatrician to have a full evaluation. I was denied the diagnosis visit with the developmental pediatrician because Skylynn had autism. They'd put the 299 medical autism code on her medical records when they sent them in to be covered. The denial said that they didn't cover this kind of mental health, and substance abuse was the technical thing that it said. I called the insurance company and said, "Why? Why did you deny this? I have insurance. Insurance should cover this kind of thing. That's why I pay for it." What has been a driving force for me, and what I will never forget is when the insurance company said, "We're sorry, and we don't cover anything because there's nothing we can do for your kid." I was reeling from the fact that she was diagnosed at all, and then my insurance company says, "There's nothing we can do for her." That was a really confusing moment, but I was not okay with someone saying that there's nothing we can do for a two-year-old. That doesn't make sense, and no one can say there's nothing you can do for my daughter. So, I went online and started researching. I saw all the different types of therapies that were available, the types of outcomes these therapies can have, how incredibly expensive they were at \$40 to \$60 to \$80 thousand a year if you're doing intense ABA, which is shown to be the most effective. Then I saw that Utah doesn't cover it at all. There was a national

movement to push states to get insurance companies to cover autism. I got involved with both the national organization fighting for this and the Utah organization fighting for insurance reform, and I was quickly part of the leadership team. We went up to the capital for three years fighting against insurance companies and the insurance lobby, which is extremely powerful, to get legislators to pass legislation that forced insurance companies in Utah to cover autism therapy. This is something that you have to do year-round when you are working on legislation, it is not just during the session, especially with really difficult legislation like mandating something to insurance companies. We spent three years working really, really, really hard on that. The third year, 2014, it passed. We passed an insurance mandate so that beginning January 1, 2016, insurance companies had to cover autism therapies. That was a huge moment. You can only imagine the kind of adrenaline rush you feel when after three years, you finally pass this. I'm definitely sure I could conquer the entire world if it was in front of me. So, I'm sitting in the cafeteria in the capital, they've just passed our legislation, and I find out that my representative was stepping down. I'd always thought about running for office. I'd figured he'd step down in a few years, but he was stepping down right then. Obviously, we passed legislation, so I can take on the entire world. Within 18 hours of finding out that my representative was stepping down, I filed to run for office. This isn't a small office; this is the Utah House of Representatives. I would later find out it was the only swing district in the entire state. I had never worked on a campaign, I was not involved in party politics. All I had done was advocate and fight as a mom on Capitol Hill. I ran for office in 2014, and I actually won on election night, and then lost two weeks later by 53 votes on the final canvas. That never happens. It was insane. But I had gotten so involved in the political world and advocacy, it had been an amazing opportunity to network. I was becoming well-known as a disability advocate and an autism advocate. In 2015, I had the opportunity to work on the Salt Lake City Mayor's campaign, then in 2016, she appointed me to her administration as a coordinator for disability rights. My entire job is working on disability rights for the city, and at this point in the state, there is not a position like mine that focuses on policies. All of it is policy, whether it's housing and transportation or police relations, it's all very high-level policies at the city level. I'm also working on legislation at the state level. I have pretty much the most incredible, best job I could possibly ever, ever have. I ran for office again in 2016, and the most unlikely thing happened, I won on election night, and then I lost again two weeks later at the final canvas. No one expects that to happen. So, it's been kind of an interesting ride, but in some ways, I'm glad I lost. I can really focus on this position, which I love. That's the professional place that I've gone that my daughter spearheaded. Because of her and my passion for her and my love of her and advocating for her, I've gotten to the place where I am, where I have my dream job, and where I get to advocate for people who have access needs with disabilities at both the state and local city level. Speaking back to my daughter because that's the more personal level, at first, we wanted to just think she had a sensory-processing disorder, that she wasn't very severe and that she was fine. But that's not the case. It is one of those things where, especially when they're young, you have some kind of test every six months. Some kind of professional wants to perform some test and can't use the one before because somehow, it's a different model, and every time we received a test, it was generally bad news. It was basically that she was more severe than we thought she was and that still continues. Just last week, I was told that she needs to drop a functioning level in the classes, so she's at the lowest functioning level because she's pretty severe.

Gerald: How old is your daughter?

Christine: She's nine. She's adorable. That's been hard. I have done it so many times, I wouldn't think it would still be a sucker punch when I'm told something like that, but it's still kind of a sucker punch. To speak about her, though, she's incredible. She's the cutest, sweetest, funniest little mischievous kid. She's so cuddly, and I hear all the time, "I thought people with autism don't cuddle." People just don't know what they're talking about, she's sweet and cuddly, and she loves crafts. She'll do anything for craft paper to cut up for crafts. She's funny. She's also kind of mischievous. We get papers home from school every day that say hour-by-hour what she was doing. They do that for all the kids in these special classes who can't verbalize, and some of the things she sends home are hilarious. She stole the microphone in an assembly and wouldn't give it back. She got mad at the lunch ladies and spit in the grapes. Now, I shouldn't think that's hilarious, but I do think it's hilarious. She's a sweetheart. I wouldn't change anything. Now, I wouldn't say that it hasn't been tough, it's been really tough. It's been really, really tough at times, but I wouldn't change it. It was hard, but she's been the most incredible thing in my entire life, not just how she's changed me and how she's propelled me into the advocacy that I'm doing now, but just her, just who she is. You can't know Skylynn and not love her. She's always the teachers' favorite because she's adorable and mischievous, and she does things that are kind of crazy. But, she's adorable. She sings everywhere. No one knows what the lyrics are. Sometimes the teacher might text me and say, "She keeps singing this song, does she sing it at home?" We'll try and figure out from the melody what song or movie it's from, and sometimes it's from something, but she just sings her gibberish all the time, and it's sweet and adorable. She's incredible. It's been a ride with her. She's far better than she was. At first, behaviors were really tough. The behaviors are a lot better now, but I won't say they are not there. She's just adorable.

Gerald: What impact has she had on your immediate family or neighbors or those who you surround yourself with, your circle of friends?

Christine: The obvious one is the advocacy, but we already talked about that. That's such a hard thing to quantify. It's such a holistic thing that she does. I think everybody's more aware and watches more the little things and how important the small things are versus what everyone else thinks is important. She let me put a band-aid on a scratch, and it was like we all celebrated. It really makes you stop and appreciate everything. I'm just smiling, but I have a hard time expressing how she's affected everybody. Does that make sense?

Gerald: It makes perfect sense. I do want to ask if I came to you, and I had a child that I was confused by and got this diagnosis of autism, what advice would you give me?

Christine: The very first thing I would do is look up these people on Facebook and join their group, Autism Parents saved me, absolutely without a doubt. I felt, at first, I was isolated, I didn't know what was happening. I just had no idea, and lucky enough, I was friends on Facebook with an acquaintance from high school who saw one of my posts and got me connected to a lunch group of a whole bunch of autism moms, and I will say that's what saved me, because you have to have the support. You have to hear stories like mine and be

able to ask questions and to just feel like you have a community. So generally, when people come to me, I say that you have to connect to the autism community. Here are the people who I can connect you with who have these different groups. They'll give you different opportunities to advocate, to talk to parents to find out who the best providers are. You can go to your doctor, and your doctor might not know where to send you. I actually hear from my doctor's office constantly, they'll call me and say, "Hey, we just had this situation, what should we do?" Because we're the experts. We've been the ones doing it. The doctors are not. Connecting with the community is no doubt the number one thing that people need to do.

Gerald: I am in awe of parents like Christine who change the system. People like her are my heroes because they take on current regulations of states and insurance companies. They are the trailblazers who make life better for other parents of children with disabilities like me. Thank you, Christine.

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