

An Orange Socks Story: Christie and Eric- Infantile Spasms and Autism Spectrum Disorder
Interview 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. Christie and Eric noticed their daughter, Elie, wasn't meeting expected milestones, and at five months old, Elie was diagnosed with infantile spasms. Elie is now 21 years old and has developmental and intellectual delays, but that doesn't prevent her from bringing pure happiness to her family, and those that get to know her.

Gerald: Christie, how old is Elie?

Christie: Elie will be 21 in two weeks.

Gerald: Okay, when did you find out that Elie had disabilities?

Christie: Well, we found out pretty early on, when Elie was three months old, we noticed that she wasn't doing new things every day like was before. She wasn't tracking us across the room, she had some odd movements she was making. We mentioned this to her pediatrician, and she said, "Oh, six months we'll do another check, and I might send you to a neurologist if there are still concerns." At five months we thought, "We don't want to wait, something is going on." So, at five months we went to see the neurologist, it was clear from when he saw her that this was a very serious situation. She has what's called infantile spasms, which is considered a medically catastrophic seizure disorder because it is highly associated with developmental disabilities and even early death. So, at five months when she was diagnosed, we realized the path that we are on was not headed in the direction that we anticipated.

Gerald: So, Eric what were your thoughts when you found out that you had a daughter with a significant disability?

Eric: Well, because it was a new experience, I had no relatives or anybody else that I was close to that had a disability. So, it was totally out of the blue, like, "Oh my word, what is this going to be like?" I mean, it was heart breaking. We were in major grief and there was that immediate overwhelming emotion on the feeling side. I remember thinking that I didn't know what to think, I didn't know what to expect. It was a whole road that we couldn't see in front of us very far.

Christie: Well, I have a cousin with a developmental disability, and I'd always wanted to be a nurse, even though I didn't end up being a nurse, so I was a little bit more comfortable with medical issues. But it was heartbreaking because I wanted children for a long time. I wanted a daughter specifically, and I had these dreams of going shopping together, and I knew that was likely not the way life was going to go. But I went right into momma bear mode about, "Okay, what do we need to know? What's next on the road?"

Gerald: So, she has a seizure disorder?

Christie: Yes, infantile spasms is a seizure disorder.

Gerald: Okay.

Christie: And it's called infantile because that particular seizure-type you'll stop having that seizure type at a fairly young age, but if it's not controlled, it moves into another seizure type. So, she was having 200 plus seizures a day. We immediately were enrolled into a study at UCLA, and that was some great support to be enrolled into a study and to have that level of care and oversight. But I did some research and I thought, "Okay how about we try this other thing? Because this medicine isn't working." The neurologist somewhat dismissed this vitamin and said, "Well, we'll try that if nothing else works." Well, eight weeks later nothing else had worked and so we tried the B6, and within three days her seizures were gone.

Gerald: Wow.

Christie: So, this in the literature, for some reason, that infantile spasms can respond to vitamin B6. They don't know if it's genetic, metabolic or what it might be in her case. Unfortunately, they went on for too long. They say that within three weeks, if you can get the seizures controlled that there will typically be a better developmental outcome. But if not, then you are looking at a fairly significant developmental disability.

Gerald: Does she have an intellectual disability as well?

Christie: Yes.

Gerald: Was it caused by the seizures do they think? Or was it part and parcel?

Christie: Part and parcel, so they don't know. It's kind of the chicken and the egg.

Gerald: Okay, tell me what it was like as she was growing up now that she is 21 years old. What was it like having her at home, Eric?

Eric: The first two or three years was, I think, a very similar experience to other parents. A friend of ours had a daughter with the same age and there were some obvious differences. Elie was non-verbal, so she didn't have the language skills that she should have. So, she kind of toddled around and they chased each other and they had a good time. But the older she became, the more distant she became from her peers and from our friend's daughter. They were huge sources of support, our friends, but it was also a daily reminder of the different road that we were on. So, it was very challenging, we had lots of therapies, we got her right into occupational therapy and speech therapy. Lots of medical appointments, metabolic studies we were doing stuff at UCLA and USC Children's Hospital all the time it seemed like. So, our lives were very full of just the logistics and the care of Elie.

Gerald: So, Christie, you had to become a big advocate for your daughter. You likely ended up knowing more about the condition than the doctors that were treating her because of the research that you had done. Why don't you tell me about some of the things that you've had to do as a parent to advocate for the best care for your daughter?

Christie: Well, research, research, research. Even though, thankfully, it was almost 21 years ago, I had fairly good internet access and I was talking with another parent. I would say get into services as soon as possible. Because Elie had a diagnosis that was so clearly associated with developmental disability, the hospital got us connected with developmental services, we were in California at the time. That set us on the road of having the necessary therapy, and speech twice a week, OT and PT. But I always felt like I had to be Elie's voice. I have to be her advocate. We know she wants to be happy. She is delightful and loves to laugh and be active and she deserves a life, a life that is not just existing, but really thriving. So, a lot of different advocacy medically speaking, but of course in school settings.

Eric: I think our first IEP was when she was three. It was much earlier than a lot of parents start that process, but it was because Christie was particularly on top of getting her into not just services, but the school system where they could then pay for a private placement. Which was pretty amazing for the time.

Gerald: And you've taken her out of state for different treatments and programs, how many times have you done that?

Christie: Well, she was out at Kennedy Krieger Institutes inpatient neurobehavioral unit on two different admissions, it's part of Jon Hopkins. Her first time there she was there for five months. The second time was seven months. It's a unit that focuses mainly on children who have autism who have what they call, "severe problem behaviors." Which is usually aggression and/or self-injury. Unfortunately, Elie developed very severe self-injury when she was about nine. She would cycle in and out of it, but at age 11 it cycled in and never came out.

Gerald: But she's not on the autism spectrum?

Christie: She is on the autism spectrum. That's a diagnosis that we got later and it was actually a very helpful diagnosis, because it helped us understand her communication, and that pictures might be a good way to communicate for her.

Gerald: Do you have other children?

Christie: Yes, we do.

Gerald: What has been the hardest things that you've had to deal with, Christie?

Christie: Well, it's certainly horrible to see your child self-injure. There is something uniquely devastating, I think, about seeing your child self-injure, and seeing that she doesn't want to do it, but she can't help herself and she needs help. So that's very difficult, and I think that if self-injury wasn't in the equation, it would be a very different experience. That has placed a layer of, "Well, you don't want that for your child, you don't want accept that." There are people who say, "Well, she is just going to have self-injury for the rest of her life," and I just think, "Nope. I'm not going to accept that. I'm going to keep pursuing treatment for her."

Gerald: Eric what's been the hardest things for you?

Eric: I think I'd have to agree with Christie with the self-injury. We've gone through the whole grief process with just the initial diagnosis and coming to terms with a child who is going to have an intellectual disability and she'll be non-verbal and we moved through that, and it was okay. But then the self-injury came along and it was a whole new thing, almost a double whammy. It was a very difficult thing to see and it did happen gradually. It cycled in and cycled out. We would think, "Okay, this is horrible, but it seems to have cleared up." But when she cycled in that became all consuming, more so than what we already thought we were consumed by. Which was the first eight years of her life. That was big. I think for me personally, the most difficult thing has been all of the advocacy. The difficulties with the state agencies, with various people and committees that we'd have to work with and sometimes against, unfortunately, to get Elie's needs met. That is very stressful for me personally.

Gerald: You placed her outside the home. Christie, do you want to talk about that? How old she was and what your thought processes were when you did that?

Christie: Right. Well, we never ever imagined placing our daughter outside the home, but when she was 11 and cycled into a very serious self-injury behavior cycle, she needed somebody with her at her side during all 18 hours to prevent her from hurting herself too much. At the time, Oregon literally did not have the funding to have in-home supports at that level. We didn't really have a choice but to place her in a group home, because otherwise she was at risk. So, in some ways that made it easier. This was a clear decision that was in her best interest. But it was horrible, when at 11 years old having your child move outside your home. But she needed it.

Gerald: Sure, so with your other children, what was her impact on them?

Christie: Well, we have one son who is five years younger, and so all of his life this is what he has known. This is what he's known his sister like. I've been very cautious from the beginning from not wanting him to feel like he's responsible for taking care of her. For him to be as much of his own person and child as he could be. I became aware of sibling workshops, sib-shops they have, and just aware of the psychological effects of having a sibling that has such demanding needs. I mean, I have to say he has been very impacted by it and we've done our best to let him have a normal life but that has often meant sending him away to do fun things with family while we stay with our daughter. It's difficult, but at the same time he has great care and concern for people with disabilities in the community and he's learned a lot.

Gerald: What has been her impact on your extended family and friends?

Eric: I would say we lived in California till she was about five, and we had a lot of immediate family there and she was part of the family. We had aunts and uncles that knew her well enough to take care of her, so we did get a break every once in a while. Few weekends away here and there. Then we came up to Oregon and I have family here as well, but that's when things started to get more challenging, so I think it was hard with our extended family. They didn't know how to be family, and we did our best, but her care was so involved at some point that we felt like we were the only ones who could take care of her. So I think a barrier almost went up, that kept them out, and they would see us and see how busy we were and how involved we were and we'd

get a lot of sympathy and a lot of help in other ways, but that didn't turn into them being intimately involved in her life.

Christie: Well, I think anytime there are particularly challenging behaviors with the self-injury, it's scary. It's scary to see it, and you don't feel equipped. It can be very scary and just too much. So, we don't expect family to get in there and to take care of her, although there have been some family members who have gone into the profession and are working with individuals with developmental disabilities and we think their exposure to Elie helped them know, it doesn't have to be scary. It can be quite delightful once you try, and so that's happened too.

Gerald: Well, that is a perfect segue. We've talked about the challenges, tell me about the joys.

Christie: I'm probably going to get teary, but Elie is pure happiness. She wants to be happy and that drives me again to get services in place for her that allow her to be her happy self. There is no purer joy than when Elie is happy. That is just an amazing, healing blessing that you just don't get from other experiences. There is just something about it.

Gerald: Eric, what are some of your joys?

Eric: I would say, Elie is Elie. There is no artifice, no manipulation. When she is happy, it is 100 percent. If somebody is able to experience her and be on her level it is amazingly rewarding and heart filling. Most of the caregivers we've had over the years have gotten to know her and inevitably love her, and there's been the odd staff that hasn't been able to do that, but she fills their heart. We have people who, to this day, cared for her when she was four or five, six and eight that want to keep in touch and see pictures and see how she is doing.

Gerald: So, you've had quite a journey. You got a diagnosis early on. A catastrophic diagnosis and later a diagnosis of autism, or now autism spectrum. You've had a lot on your plate in terms of advocacy, and you placed her in programs when she was 11 to protect herself from injury. There may be another parent that is going through the same thing now, that you went through a decade ago with your daughter. What advice would you give them?

Christie: Reach out, in our daughter's case she has a relatively, rare and complicated form of self-injury. We tried everything, is she not feeling well? Is there something that she is struggling with? Full medical work-ups and tried everything and we just weren't getting anywhere. We were told, "Well, you might as well just let her self-injure and she'll figure out how to stop." And I just felt like, "No, I don't think that's the case, plus I can't watch my daughter hurt herself so severely." So, calling, and trying everything and reaching out to professionals. Thankfully, with the internet, you can find what you need with parents. It's easy to let yourself be isolated because it's just all-consuming to take care of your child, but one step in front of the other, don't take on too much at a time. But reach out to parents.

Gerald: Eric, what would your advice be?

Eric: It is easily isolating, or easy to be isolated. You get so involved and wrapped up in their care and it just feels like nobody else can do this. We've had interactions with other parents who

they can see that's the case. We've been there ourselves we were almost forced to let go of that ten years ago when we had to have her placed. Try to break out of that and realize that there are people who want to help. Let them, they are going to need to know how to help. You're going to need to educate them and express the ways that they can express with the child, or with you. There were a lot of times where I needed support and I didn't know how to ask for it. I think I would be a lot better now about reaching out to friends who say go do something, even if it's just for a couple of hours.

Gerald: Anything you want to say otherwise that I haven't asked?

Eric: If we had to face this again, or if we met parents that were in our exact same shoes. Well, I would first say that we would do everything that we could to help them. But the big thing is not just dealing with the diagnosis and everything that is going on, but the services and the advocacy. Unfortunately, a lot of people are just not equipped, that's some pretty unique tools to have under your tool belt to know how to do that. We are pretty lucky Christie has been amazing at that, and that's kind of in her wheelhouse to do that. You've testified in front of committees, so not just advocacy for Elie, but for the whole autism community and for kids that have self-injury.

Thanks for listening to this episode. 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.