

An Orange Socks Story - Caitlin and Dallin: Spinal Muscular Atrophy

Interview by: Gerald Nebeker, President of Orange Socks

What a great pleasure it was for me to go into the home of Caitlin and Dallin for an Orange Socks interview about their daughter, Auni. Their story is very tender. A few months after her birth, Auni was diagnosed with spinal muscular atrophy, or SMA type 1. SMA, it is a fatal condition, and Auni blessed everyone's life for 21 months before she passed away. I appreciate Caitlin and Dallin for sharing their beautiful and heart felt story.

Gerald: Dallin and Caitlin, thank you for meeting with me. This is awesome to be in your home to talk about your daughter, Auni, who had spinal muscular atrophy. Auni passed away a year and a half ago.

Caitlin: It was September of 2015.

Gerald: Okay, Caitlin, when did you find out that Auni had Type 1 SMA?

Caitlin: When she was about three or four months, we noticed something was wrong. We weren't sure exactly what, so we went in for testing of physical therapy. She was seven months when we got the diagnosis, which is pretty late. I think most other families with this diagnosis usually find out within the first one to four months.

Gerald: Dallin, what did you think when you heard that diagnosis?

Dallin: Shocked and overwhelmed. We had googled it, which was a mistake. She was three or four months old and she couldn't really sit up, she couldn't really support any of her weight, that's when we knew something was up, so we googled.

Caitlin: Her not being able to bear weight on her legs.

Dallin: Yeah, her not being able to bear weight, and SMA came up, and we saw that the statistic was that like 90% don't live past their second birthday.

Caitlin: Which I don't think we knew that initially, we just knew that it would take her life.

Dallin: And early.

Caitlin: So, at that point we didn't know what was going to happen. So, we decided to not think that way, we couldn't scare ourselves yet.

Dallin: That was before we had done any testing. We just said, "Alright, we'll just take it as it comes," and that ended up being her diagnosis. The worst-case scenario for us had come true.

Caitlin: And that's because we knew the end result that that would end up taking her life. That's all we knew about it; you know what I mean? We didn't know anything else.

Gerald: So essentially, it is a fatal diagnosis?

Caitlin: Yeah.

Gerald: It's just a matter of when.

Caitlin: Yeah, it's terminal and you just never know when.

Gerald: But it is typical for the children to pass before the age of two?

Caitlin: So, the statistics numbers are 50% don't live past their first birthday, 90% don't make it past their second birthday. There are four different types, and it's all about the highest milestone reached and the age of onset, if that makes sense. So, most type 1's never sit up, Auni lifted her head up then lost that. Some type 1's will roll over and then not be able to anymore, but mainly that she was never able to sit up is what kind of made her type 1, she was a stronger type 1.

Gerald: Okay, so what were some of your thoughts initially? I mean, we have Dallin's thoughts, what were you thinking now you're the mom of this kid with this great, long-named diagnosis?

Caitlin: Yeah, it was absolutely terrifying. I'm going to get emotional, but just hearing it was, just time slowed. It just didn't seem real, you know, just, "Oh, she has that thing we researched, and it's going to end up taking her life." The lady that diagnosed her was so sweet, but didn't know too much about it. We were then referred to a pulmonologist for breathing on a Monday, and she was diagnosed that Friday. That is when we were first introduced to the medical side of things. I just remember driving home, Auni just babbling in her car seat, and me and Dallin just silent, just sobbing the whole way home. You don't know how to process it. Family and friends were texting us and calling us, we didn't respond. We knew we couldn't put it off till the next day to tell them. That night we went over to both of our immediate families and told them.

Dallin: That was hard.

Caitlin: Yeah, it was a little overwhelming, and definitely heart breaking.

Dallin: They knew we had gone to the doctor and knew we would get answers, so they were expecting a result.

Caitlin: The fact that we weren't getting back to them, they knew it was bad.

Dallin: So, to have to go deliver that news to grandma and grandpa, and uncles and aunts that it was bad news. It was hard, really hard.

Gerald: So, she lived right up to almost her second birthday.

Caitlin: Yeah, she was 21 months, so.

Gerald: 21 months, so Dallin, during that 21 months, what was the hardest part either in caring for or dealing with the diagnosis? Or what was the hardest part for you with Auni?

Dallin: I think just seeing her just deteriorate slowly and lose physical things that she could do. We knew that would happen with the disease. Their muscles don't develop and continue to get weaker. So, just to see the actual disease take its toll for her to lose, you know, one thing after another. You can kind of tell, you know, things are getting worse because she's getting weaker. Things that we used to be able to do, hold her up, you know, she needs to stay horizontal now, and she struggles a little bit more breathing. Those were the sort of things that were an indication that the disease was taking its toll. It was hard to see, especially because kids with SMA are unaffected mentally. So, she was growing like any toddler would and we could have that relationship, but her body was breaking down.

Gerald: Sure, what was the hardest things for you, Caitlin?

Caitlin: I would say, I'm a stress case, everyone in my life knows that I stress just about everything. So, it was just, just the pressure and the stress of doing everything right, and learning all the medical equipment. Also, just the looming of how and when she would pass away. I was scared that it maybe would be traumatic, or like in a public place where she would stop breathing. A lot of other SMA parents have episodes like that, and so that was always looming. Her care was pretty overwhelming too. In the moment, you're trying not to sink, just your head is out of water, but you're doing it and slowly it gets better. But that first initial almost fog of right after they are diagnosed, you're thinking about all the "what if's," and you're stressing about everything that your future now is going to look like. Trying to adjust those views of what you thought it was going to be and now, "Holy cow, I've walked into this big dark scary tunnel and it doesn't seem like you can see a light at the end."

Gerald: Sure, easier question, what were the joys?

Caitlin: A lot. You'd look at her and she was always happy. She didn't know any different, and she was so happy through everything. Just being a parent is the most incredible thing. So even though losing her was really hard, when she was here just the stress of it all, you'd take it back in one second. Just to be able to spend any more time with her because it was just so precious, and she was so resilient and so positive and happy and had such a positive impact.

Gerald: And Dallin, what were your joys?

Dallin: Just knowing that her days are numbered, you know, and so with that in mind you kind of look at everyday as a gift. Every day that you have with them is special. I think when your kids are healthy, it's easy to kind of lose sight of that. Every day you get to spend with a child is special, but especially if their days are numbered. We were able to keep that outlook, that every day we have her is the best day, just a gift.

Gerald: What impact did her 21 months have on your extended family and your circle of friends, Caitlin?

Caitlin: It was pretty incredible. I feel like as soon as she was diagnosed our families, but also our community, just really rallied behind us. I mean fundraisers were put on weeks or days after she was diagnosed. I feel like so many people were affected, and it's kind of became therapy for me to share updates and our story over social media. It was the easiest way to update everyone just in one place, and so a lot of people were able to get to know Auni. SMA is a respiratory illness and so colds are pretty serious, but people don't think about that and so we had to be careful where we take her. A lot of people weren't able to get to know her in person, whereas normally they could without that stress. So that was really nice, but I feel like she had a really positive impact. I feel like she just brought perspective to ourselves, family and friends, just of what's truly important.

Dallin: And we've kind of found that it is easier to just be on our kids' social media, just to be real with how things really are. I mean, early on we'd kind of hide the hard days.

Caitlin: Kind of just pretend.

Dallin: Emphasize the good day, I feel like deep down inside we were just hurting. Once we started sharing the good and the bad, that's when people started to relate. That's when people loved hearing Auni's story and hearing how she's doing and seeing her videos and her pictures. She had quite a following. We were just grateful that people were able to get to know her like we knew her, but through social media. In a way that they couldn't do in person.

Caitlin: Before we started sharing, we would kind of just pretend to be happy, just not thinking about it. Naturally, you kind of pretend to be okay, and kind of hold it

together out in public. But once we started opening up, it was a release for us, just not having to be so miserable. We were suffering behind the scenes and we didn't get that support.

Gerald: If I were to come to you seeking advice that I just found out that my child had the same diagnosis, what advice would you give me?

Caitlin: I would first say it gets better. The fog lifts and you find a new normal, even in the process there is always happiness. You can find joy in every day. It's just noticing it and it's usually in the small things. Even just a simple walk with Auni, going to the park and laying on a blanket, not having her hooked up to her pulse aux. Just a normal moment. We just don't take any of those for granted. But initially, I would say it gets better, it takes time and it's overwhelming. Just take it one day at a time and that fog will just slowly lift, and you'll kind of find your new groove. You'll experience happiness even though it's going to be so hard, but so worth it, always.

Dallin: I would say to get the medical care information from your doctors. I would reach out and talk to other families. I would also establish your new routine as far as what you do for your child's care. We naturally developed a routine of how we would handle care for Auni. Our routine worked. It was great, she had her schedule, she had her routine. There were times where she was in the hospital and we'd come home and pick right back up on the routine. She wouldn't even miss a beat and for us. As parents, you get a routine and you kind of get a grasp of her medical care. We essentially had an ICU of medical equipment in a room with the stuff that she would need. At first it was overwhelming. You'd just see all this medication and you think there's just no way that you think you can do it. Then after a month or two months, you're an expert.

Caitlin: You're just so used to doing it.

Dallin: There was a two-week stint that she spent in the hospital, and essentially the respiratory therapist told us we were qualified to do their job as respiratory therapists, just because of what you do at home.

Caitlin: SMA's, their treatments are so aggressive.

Dallin: And so, you just take the information and equipment and set it up in your home.

Caitlin: What was very helpful for us, is I remember I went to that appointment and we learned how to do her breathing treatments that you're supposed to do as preventative care twice a day, and then if she gets sick, every four hours around the clock. But we learned that treatment, and then we went and met with a group called rainbow kids. I don't know that it is a palliative care team, I don't know for sure, but it was a social worker a nurse and a doctor. They sat us down and gave us a timeline of SMA. They said this is what's going to happen, here are your options as a parent.

Don't let the doctors make you feel one way or another. You have to do what you feel is best for your child and your family. I feel like that helped us because they were able to say this is what life with a trach looks like, this is what a life with just doing the bi-pap would look like and where it would lead. They helped us know how to ask those really hard questions. It was scary, but got us thinking about those. I feel like we were way more prepared when actually faced with those decisions, it was a huge help.

Dallin: It's difficult to have that because one, you're dealing with a diagnosis emotionally, then you have to answer questions like, "How much medical care do you want to give them?"

Caitlin: Like if an ambulance was called, or she was coding or something, just what would interventions would they do, where it would help her or hinder. Their body gets so frail, doing CPR cause more issues then it would help at that point. Just those kinds of tough decisions.

Dallin: And when you're just emotionally shocked to have to deal, that was pretty tough. But it's so important because when you get to the end of the road, you've made all the tough decisions. You've already thought it through, you know what you're going to do.

Caitlin: It's still terrifying, but you at least feel more prepared or more informed so you can at least make a better decision. That was kind of the scary thing for me just even in the hospital making tough decisions. In an emergency situation, if an ambulance called, usually the ambulance crew doesn't know a lot about SMA. Many times, you know more as a parent. That was kind of terrifying and a lot of pressure too, like no one knows how to take care of Auni better than us, besides us.

Gerald: Wow, super, any final words?

Caitlin: Going through it all was so hard. We've learned a ton and we've grown a ton, but we wouldn't change a thing. That's the craziest part through it all, even losing her. We'd want her back in two seconds if we could. But the people we are today, it's because we had Auni, and all that we went through.

Dallin: As parents we just gained a greater appreciation for life in general, but for our kids and our nieces and nephews. We look at them and they are healthy, and they are happy and the miracle that is. I think you can take that for granted because you see it everywhere. But when you lose a child to a disease, you have such an appreciation for young kids that are healthy, and just life with them in general. It's such a joy that I think often gets taken for granted. So, for us it keeps life in perspective.

Caitlin: And I hope we can keep that perspective because I know we are going to fall into that too with more children. If they are a toddler or making messes or throwing

fits that will kind of be fogged. But they have muscles that are working, they are happy they are healthy. They can throw a fit, they can throw themselves on the floor. They have working muscles, and so it will be a miracle to see a child meet those physical milestones. Hopefully we can keep that gratitude and perspective.

Gerald: Oh, I appreciate it and I appreciate you two taking the time. Caitlin and Dallin, thank you. Thank you for doing this interview with me.

Caitlin: And thank you, this is so nice of you.

Gerald: Appreciate it.

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