

An Orange Socks Story: Laura and Devin-Down syndrome
Interview by: Gerald Nebeker, President of Orange Socks

Gerald: Welcome to the Orange Socks Podcast with Dr. Gerald Nebeker, where we feature inspiring lives despite a diagnosis. Today's episode is number 76, Laura and Devin. In this episode, I speak with Laura and Devin about Annie, Laura's adult sister with Down syndrome, who lives with them and over whom Laura and Devin have legal guardianship. I know you are going to love hearing their story.

Gerald: Laura and Devin, thank you so much for taking the time for an Orange Socks interview. Laura, your sister Annie lives with you. I believe you were eight years old when she was born. Tell me some of your thoughts, what do you remember about your sister's early life or when she was born?

Laura: Annie is actually a twin. My parents came home and told us that they were expecting twins, and we were excited. It was a boy and a girl, and they were going to be for sure the caboose to our family as they would be children five and six. My parents were excited to have these two come. When she was born, my parents had no idea that Annie had Down syndrome. My mom had forgone doing any amniocentesis or anything like that, so it was a complete surprise. I remember my parents telling us what Down syndrome was, and I remember that there were times in our family that we have said, "retarded," or we made fun of people with disabilities, but now we had a sister with this disability, and we had to make sure we were really sensitive to that. I remember in my eight-year-old brain a time that we were at the dinner table and someone told a joke about a retard. Now our family is aghast, we would never say that word because we understand better than we did then. It was just ignorance, but those are some of my earlier memories. When I was about ten and Annie was two years old, I didn't have a great relationship with her. I remember one night laying on my bed crying, and my mom came in and asked what was wrong. I said that my sister Amanda had a relationship with Annie, and my sister had a good relationship with Julia and Daniel, her twin, and I didn't have anyone. I didn't know why I wasn't close to anyone. My mother said, "If you want to build a relationship with someone, then you need to spend time with them. Start spending time with whoever you want to have a relationship with." So, I figured if I wanted to have a relationship with Annie, that's what I needed to do. I started spending a lot of time with her. Annie loved to swing outside, so I would go and swing with Annie. She wasn't quite able at that age to do monkey bars, but as she got older and wanted to do monkey bars, I'd go out and do that with her. I remember my mom saying things like, "It's so great that you're doing that because those are some muscle-tone things they are working on in OT, and we're grateful that you're spending that time with her." As I did that, Annie and I just got closer and closer. When we would go on family vacations, since it's mostly girls in my family, all the sisters would take turns helping with the younger kids, but I would spend time with Annie. I would give her piggy-back rides as we'd be traveling to different places, and we just kind of developed a relationship that way. In high school, I ran a group that

was very similar to Best Buddies for anyone with an intellectual or physical disability. We would not sit up in the stadium, we would sit down on the grass on the lawn. Annie came with me every single time we did that. Just because of those kinds of things, people at my high school knew who Annie was, and they knew us as buddies being together. I'll add that any of these things that I'm saying about the Best Buddies program was completely my mom's idea. She suggested I do it, and as I look back, I'm grateful for some of those things that my mom put into my mind. She saw a couple who had won homecoming king and queen at a different school, and they were interviewed in the local newspaper. Their parents said that the main reason they had so much notoriety within the school was because of this Best Buddies program. When my mom saw neighboring schools doing that, she said, "Hey, you should start that at your school, that would be so cool." She gave me a lot of ideas that kind of helped me to know how to help, and it really solidified the relationship between Annie and me.

Gerald: What was it like with your friends? When you had friends over, were you the friend with a different sister? How did your friends accept Annie, or did that have any effect on any of your friendships?

Laura: Never a negative effect, if anything, only positive. People loved Annie. She has always been full of love and warmth, so people love to sit and play with her because she was fun to play with. People loved that she loves to give hugs. I had a friend who also had a sister with Down syndrome, and people knew that both of us had a sister with Down syndrome, so there was never any negative talk about Annie or my friend's sister. It was always a really positive thing, like, "Oh, that's so great that you have a sister with Down syndrome."

Gerald: How did Annie in your life affect your dating relationships and now your husband's when you were first going out and then got engaged?

Laura: I think Devin knew that Annie and I had a special relationship.

Devin: Yeah.

Laura: Just because Annie and I had always been really good friends, as Devin and I were dating and as things got more serious and we were engaged, before we got married I said, "I just want you to know that if we get married, you have to be okay with eventually down the line being willing to have Annie in our home. We've always been so close that it has always been my thought that if something happened to my parents or as my parents age, Annie's going to need to go somewhere, and I want it to be with me. Are you okay with that?" He said, "Yeah, of course, I'd be happy to have her." Devin was always great with Annie, but he had to have a little training about not saying the word "retarded."

Devin: Yeah.

Laura: That was when we first got married, but again, it was an ignorance thing.

Devin: We were dating at that point.

Laura: Yeah, we were.

Devin: It was.

Laura: He took care of it before we got married.

Gerald: Devin, what were your thoughts? You're dating this young woman you want to marry, and she's got a sister who might come live with you. What were you thinking?

Devin: At first, it was just okay, that's somewhere down the line, but it wasn't like we weren't spending a lot of time with Annie anyway. We were always over at her family's house, and I got to know Annie pretty well quickly, aside from my usual uncouth word.

Laura: It didn't scare you off?

Devin: No, not at all.

Gerald: You got married, and at some point, Annie came to live with you. Were you the designated sister somehow?

Laura: There's kind of a big story behind that. Right after we got married, my mom and Annie's twin brother had both battled cancer. Before we got married, my brother had leukemia, and my mom had breast cancer, so they went through their cancer battle together. When we got married, they were both in remission. We were ecstatic, we thought that was going to go on forever, and we were super hopeful. We were both sure they were going to live well into old age, but very quickly three months after we were married, my brother was re-diagnosed with leukemia, and not only did he relapse, he passed away three weeks after he was re-diagnosed.

Gerald: Oh, my.

Laura: It was devastating for our whole family. We were just very upset about it. Annie took it horribly. It was her twin brother, and people say that twins have a special bond, and they do.

Gerald: How old was Annie at that time?

Laura: Annie was 12.

Gerald: So, her twin brother then died at age 12.

Laura: Yes, they were fraternal twins, so Daniel did not have Down syndrome. My parents said that it was such a blessing that Daniel and Annie were born together, because growing up, when Daniel would start to crawl, Annie would watch him. She had this built-in role model who just showed her all these developmental milestones and what to do next. Because of that, Annie is extremely bright. She progressed really well in school. She was not exclusively in a regular-ed classroom. They did an inclusion model that included some special-ed classes, but she very much was with her regular peers. Most of that was because she had my brother Daniel who was her twin, and she also has a sister who's 22 months older than her, so between those two little buddies, she had these great peers that helped her do really well. Annie was devastated and it affected her. Not only did Daniel pass away, my mom was re-diagnosed with breast cancer at the same time, and lung cancer, and bone cancer and brain cancer. It's like it just kept coming. It was a real struggle, because not only had my brother just died, my mom was extremely sick. At that time, I had been going to school to teach special education, so I already knew a little bit about the IEP process. I knew a little bit about what services kids got and stuff like that, so because of that, it kind of fell in and I was able to start helping. I also was in the middle of going to college, and my mom had always denied doing any kind of respite services, she would say, "My family will take care of it." We had an amazing case worker at the time, her name was Lorena. She said to my mom, "You know what, Sandra? I know you've always said no to respite services, but I think you've hit a point in your life where you have cancer, and might need a little extra help. It can be someone within the family." She said to me, "Hey, you're going to school, and you have a flexible schedule. Why don't you do respite?" So, I started doing respite with Annie, so because of that, it became my job, and it just kind of fell in naturally. We always made sure that the first week of school we would go with Annie so that she didn't have to have an aide take her from class to class at junior high and navigate the campus. One of us would go with her. My mom used to go with her, but I just kind of took over and started doing that, so I developed a rapport with her teachers and continued that relationship with Annie. I took over that and while I was spending all this time with Annie, my mom realized the fragility of life. She knew that she might not be around forever, so we started talking a lot about what would happen to Annie. It was a very regular conversation. I would say that my mom and I talked about it every two weeks at least. She would bring it up, or I would bring it up, and my mom kind of laid out things that she wanted for Annie. She made it very clear that she wanted Annie to graduate with her peer group, she didn't want Annie to be at school additional years because Annie had gone to school all this time with her same peers, they knew her. We always joke and say Annie was a celebrity on campus as she would walk around the school.

Devin: She was.

Laura: Right. Everyone knew who she was, when she had her 16th birthday party, a hundred kids showed up. That's just how Annie was. My mom said that she's got to graduate when she's 18. She told me other things as well, and she told me things she

envisioned. She said, "I want to make sure she lives in a house where there is always life, where there are new babies and a family that's growing." She talked about eventually living in a house where she could have maybe her own mother-in-law suite, where she could live and still be a part of a family but have some independence. She talked about Annie serving a mission, going on to college. She talked about Annie hopefully getting married someday and having a relationship where she could feel like she was the same as her sisters. I remember asking, "How does that work? Do you really think she could marry someone?" My mom said, "Sure, why not?" Because we talked about all these things, it kind of cemented in my mind some things that she thought would work for Annie. I remember her talking to me because I was a teacher, saying "Wouldn't it be great if later on in life, you and Annie ran a preschool together?" It's interesting because so many of these things that we talked about have come to fruition. I think it's because she laid that groundwork, she had envisioned a life for Annie, and that's what she did her whole life. She had these goals for Annie, and she would make them happen. She had envisioned this life for Annie and talked about it to me so much. Almost every single thing has happened. Well, not everything, because Annie's not married yet, but she will tell you the first thing as soon as you meet her that she's looking for the right guy.

Devin: I think the exact verbiage is, "When I meet a cute guy I like."

Laura: It is, yeah. That was really helpful that my mom did that. My mom passed away really quickly after my brother, only nine months after my brother did. Annie was young, only 13, and it was hard. Lest you think I did any of this alone, it was totally a family effort. I have a sister who at the time had moved in with my family to help because everyone had cancer. Her name is Emily, and when my mom died, she said, "Okay, Daniel's gone, but there are still these two sisters at home." I had a sister named Julia who was 15 when my mom died, and there was Annie who was 13. We said, "We're going to be a power team." Emily said that she would take Julia because Emily and Julia had a really strong relationship, and she said that I would take Annie. I said, "Okay, let's do this." My mom passed away in June, and in August, Emily and I went to all of the back-to-school classes and met the teachers. We were going around and talking to their high school teachers, trying to figure out what the girls needed, reading their syllabus and getting their supplies. We just looked at each other and kept realizing that really, this is our job. I was 21 and Emily was 27, we were young to be navigating high school and to be acting that way, but it's what needed to happen, it's how we went forward.

Gerald: Let me ask a question about impact. You're newlyweds. How long had you been married when Annie came to live with you?

Laura: Three years.

Devin: Three years.

Gerald: Did you have other children by then?

Laura: Not yet.

Gerald: Okay, all of a sudden, you're still newlyweds, and three years later, you have someone in your home, your wife's sister. What were you thinking in terms of that, in terms now there are these other financial and health responsibilities? What were some of your thoughts?

Devin: I think that as far as Annie coming to live with us, it wasn't just an event that occurred like a discrete event, it was kind of faded in, if you will. We would spend our weekends and our evenings at the family's house, and we would all eat dinner together. Then as time went on with various circumstances, it became more obvious that Annie was going to live with us. In about 2010 when we had been married for about three and a half years, we rented a bigger house and Annie lived with us. Emily and Julia came along for the ride, too, so we just had a big family home that we all lived in for a couple of years. Eventually, when Annie was turning 18, we obtained guardianship. So, it was kind of a fade-in from we hung out with Annie when we were dating and first married, to okay, we are taking care of Annie more on a daily and nightly basis, to then Annie comes and lives with us with the other sisters as well, then we become her guardian. It was a process, not a drastic change.

Gerald: So, you obviously developed a love for and an appreciation for Annie early on.

Devin: Yeah.

Gerald: Let's fast forward a little bit. You moved from where you were to another place, you're going to school and all that. You've had how many other children?

Laura: We have three.

Gerald: So, in some ways, Annie is kind of a built-in baby sitter, and in other ways, she is part of your preschool program just like your mom envisioned. What's it like to have her at that level and have her interacting with your children, and what is her impact on them?

Laura: One answer to that as we tried to figure out where Annie would go because there were other sisters willing to take her, was that it was a good thing that Devin and I didn't have children when Annie first came to live with us. As we did have children, Annie would just be a person in our household. It wasn't like a new thing. Annie has always had an amazing relationship with our kids. As we've had each of our kids, it has just been phenomenal to watch her. We call Annie "the baby whisperer," because she can put any kid to bed and helps them fall asleep so well and easily. Annie loves babies, I mean absolutely adores them. If she goes anywhere and someone has a baby, she's asking if she can hold them. She's great with kids.

She'll tell you that as soon as they can talk back and get sassy, she says they are not so fun anymore.

Gerald: I have the same opinion.

Laura: Right?

Gerald: I'll hold them while they are good.

Devin: It's an interesting relationship that Annie has with our kids. Not the new baby, but as the boys are getting older, it's a fluid relationship. Sometimes it's more of where Annie is the aunt and more of an authority figure, and has the ability to tell them what to do, but sometimes it kind of flows into almost a quasi-sibling relationship. They'll fight and bicker, and someone comes away crying, and they flip a coin as to who it's going to be. It has been interesting trying to navigate that as far as whether the kids have to listen to Annie when she's bossing them or not. That's been interesting.

Gerald: That is interesting.

Laura: We have a sister who has a 14-year-old daughter who babysits, and sometimes we see similarities between Annie and that 14-year-old because just as they have a hard time understanding that this daughter is the babysitter sometimes and she has authority there, sometimes she's the sibling. That can be how it is with Annie, because she is the authority figure at times because of how she helps and watches them, but then there are times where she just needs to let us parent and not step in so much. It is funny though, because when our oldest boy, Gabe, who is six now was about three years old, he said to me, "Mom, why do we have an auntie at our house? Everyone has a mom and a dad and brothers and sisters, but we have an auntie?" He was pretty quick to observe that, and I said, "We're just really lucky because you have an extra person who will love you and who will help take care of you." He accepted it, but kids do notice that they have an extra person there that most people don't have.

Gerald: Interesting. How long is Annie going to live with you? She's been here how long? She's now 23?

Laura: She has been with us for seven years.

Gerald: Do you think she is going to be with you as long as she lives?

Laura: We hope so. She always tells us that she's going to move and live with her husband, but I always say, "You're not allowed to leave me. I'm sorry, but you can't." I've become just as attached to her as my own kid because we spend so much time together, and I always tell her that she can get married, but only if she lives next door.

Gerald: Devin, what advice would you give to somebody marrying into a family with a sibling with a disability and perhaps with the opportunity down the road of ending up under your roof? What advice would you give me?

Devin: I'm hardly qualified to give advice on any subject, much less that one.

Laura: Devin's very humble.

Devin: I can only speak to my experience, and my experience is that in general, I'm pretty mellow and a "whatever is clever" sort of thing. It wasn't a big deal to me that Annie would be living with us or the other sisters. I guess that's just my personality. As far as day to day, I think you just have to go through it, get into it, figure it out as it goes. Every person is unique, they have different characteristics. Just learn about each other's characteristics and each other's personalities. I remember that there was a point where I realized that to some degree, I'm Annie's disciplinarian, and I didn't entirely feel comfortable with that. It was hard to figure out how we could get along as effectively as siblings. At the same time, there are certain times when Annie does something and I say, "Okay, Annie, you gotta not do that." You have to figure out how to be a brother/father, and then as time goes on, and as you forward that relationship, your love and your bond deepens. I think Annie and I have mutual love, respect and trust. I think sometimes we team up against Laura. Time and patience and trying to do right by each other is the best way. I don't know if there is some test or anything of whether this is going to work or not. Sometimes you just take what life gives you and make the best out of it.

Gerald: Super. Laura, how has having a younger sister with disabilities, in this case Down syndrome, impacted your life?

Laura: I can honestly say that my relationship with Annie and the way I mentioned earlier that my mom helped guide me through some things has really shaped much of my life. It was because of Annie that I became a special ed teacher. It was because of her that I did a lot of the things that I did even in high school. Moving forward, even the field of law that Devin is in right now, is because of Annie. He works trying to help people with different developmental or physical disabilities get the help that they need. In the educational setting, we are doing that because of experiences Annie had in school. It has opened our eyes to the different needs that people have and how, as a community, we can come together and help them get those needs met. It may sound redundant, but there's so much more to celebrate in our sameness than our differences. It has put us on that path and really helped me feel like there's so much to be said about the importance of education. That's both of our passions, making sure that people get the education they need.

Gerald: Do you have any other comments or things you'd like to say?

Laura: There are two things I can think of. One is that when my brother first passed away, I said to Devin, "Remember how I said in 20 years we might have Annie? Well, go ahead and bring that forward about five years until we had her." Granted, we had been married three months, so it took him back. However, since that moment of having a slight hesitation, which nobody could fault him for, a friend asked me later, "Annie's been with you guys for a while. Does Devin ever complain about it? Does he ever complain about having Annie?" I thought about it and said, "Not once. There's not been a single time that he's said that he wished Annie didn't live with us, or it's so hard having her." If anything, it's me that at times has said, "Man, it's hard having Annie in our home." It's hard to balance her schedule. A lot of times I'm trying to care for someone who is 23 while going to college and trying to juggle the needs of three- and four-year-olds. As a mother, I'm still very much in the baby phase, so that disparity can be difficult. So, I said, "If anything, it's me who says that this is so hard, and he just says that, "It's okay, we'll figure it out." Their relationship is incredibly special. Like he said, they team up against me sometimes. If I'm being unrealistic, he is the first to make sure that she has what she needs. If he makes smoothies for us at night, he makes sure to go and offer. It's always his first thought to make sure she has everything she needs. I've learned from him how to be a better guardian and how to show her more love when there are times where I feel like I'm being selfish. The other thing about having Annie in our home is that I think it's hard to state the impact of having her in our home. Since she was a very young child, Annie has always been really sensitive to contention, so when younger kids in our family start bickering, it really affects her to the point that if she feels like there's tension in the home, she'll get emotional and start crying about it. Then we have the immediate sense of we have to calm down, have to do better here. Annie is so quick to show love. She'll apologize if she does something wrong, and she hates it if she and I are having tension for whatever reason. She'll say, "I'm sorry if I did something," or "Hey, let's be friends, let's get along better." She does that with our kids, too. I've always been really impressed with the amount of time Annie takes with our three children individually. You can see her outside jumping with one of them on the trampoline, just building that relationship. She'll play Uno or sit and play board games with them because she still enjoys some of the things that they do. She'll sit on the couch and watch movies with them, and she enjoys it just as much as they do. Seeing her develop that relationship with them is so special. I don't know that my kids will ever understand just how much impact she had on especially their zero to two years.

Devin: Just her example of being a peacemaker or being a person who likes to occasionally be silly and have fun has influenced our kids. They are very kind and kind of whacky, and all these different characteristics can be traced back to Annie if you really sit down and think about it.

Laura: Yeah, for sure. I think that Annie is so good at being consistent with them. Annie really likes routine, so she is really good at making sure we read with them at night and just go through all those steps.

Devin: The other night she asked if you had given Violet her medicine, and you hadn't.

Laura: Yeah, she reminds me of things sometimes. It's so interesting because it does vacillate between sibling and authority figure, and at times it vacillates between Annie and us, like we are her guardians but she also helps us to such a high degree. The more time I've spent with Annie, the more I realize that Annie is just a sibling. We tease each other and at times fight with each other. We get along for the most part, but Annie has her own unique set of characteristics, some because of her disability and some just because she is a unique person like everyone else. She's a sibling first and foremost, so there are things that are going to annoy you, but there are also things that you're just going to love. Annie shares the inside jokes that our family has. She sometimes will make jokes out of the blue where you really pay attention to our family culture because she makes a joke that is a throwback kind of joke that we say all the time. My biggest advice is to pay attention to the similarities, not the differences, because really there are more of those. There's something to be said for the genetic component where you still come from the same gene pool, so there are going to be a lot of similar likes that you have as you grow up in the same family. You're having similar experiences, and I think that has been something that as Annie matures and gets older, and because she is developmentally delayed, takes a little bit longer for me to see some of these things come through. I've noticed that the older she gets, the more I see that she's just the same as me; we are buddies just like I am with my other sisters.

Gerald: Awesome, thanks.

Gerald: I learned a lot from my Orange Socks interview with Laura and Devin. After the interview as we sat chatting, Laura said something I found very profound. Because she is the guardian of her sister Annie, Laura must make a shift in her head depending on the situation, she must decide, "Am I the guardian right now, or am I the sister right now?" Weighing the roles she should play is not something I had considered before in a situation where a sibling is granted guardianship.