

An Orange Socks Story: Janalen and Rocky – Prader Willis Syndrome and Cystic Fibrosis,  
Adoption, and Down Syndrome  
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. In this episode, I talk with Janalen and Rocky, who have 8 children, 5 of whom are adopted. 2 of their biological children have cystic fibrosis, and one of those has Prader-Willis syndrome. One of their adopted children, who is from China, has Down syndrome.

Janalen: When Katy was born, she was full term, but really low muscle tone, low birth weight. We could just tell something was wrong. She couldn't suck, she never cried. We found out she had cystic fibrosis really quickly. We just did her blood right away since it's a genetic disease. And her sister had it, so we did that quickly and found out within a few days. But knew that her symptoms were not the cystic fibrosis. And so, it took a couple months and we ended up in the hospital, just after a rough weekend. And they realized she had a collapsed lung at the time. And so, we stayed for about two weeks, but at least in that time we could see doctors. We had doctors' appointments set with a neurologist and all sorts of people in Houston, Texas. It was just really busy and hard to get in to some of those doctors. So, while we were inpatient, we got to run lots of tests and send off her chromosome testing. Found out a few weeks later that she had Prader Willis syndrome.

Gerald: So that was detectable with the chromosome?

Janalen: Yes, Yeah she has a deletion on one of her chromosomes.

Gerald: Everyone with that diagnosis has that same chromosome...

Janalen: No. I believe there's three ways, if I remember, that you can have it. There's like 70, some percent, that have how she does. She has a slight deletion on the paternal chromosome 15. Some get it by having two maternal 15. There's a few that have an actual genetic defect on the 15 that can cause it. So, if you have a child with that you can actually have a chance of having another child with it, because it's a genetic. Hers just happens, kind of like Down syndrome with Emma, where-

Gerald: Yep.

Janalen: Just and extra. And hers was just a deletion on one. So.

Gerald: Okay.

Janalen: Yup.

Gerald: So, two kids, both with cystic fibrosis, one with an add on.

Janalen: Yeah, and that first year was a lot. A lot of care, Katy's first year.

Gerald: Tell me about that.

Janalen: After she was hospitalized, we had to give her a g-tube to eat, she couldn't suck. And so just feeding her through the g-tube took time. Because of her cystic fibrosis we also had to do treatments at least 4 times a day. We had to do manual chest PT on her, she was only 5 pounds, probably at the time, or 6. So to do manual chest PT and then nebulize treatments. She had another machine called an IPV machine, that kind of would help force air into her lungs and suck it back out, for several months. She was on oxygen for about 9 months. So, just keeping up with her care all day, every day. Medications and all of that, we were a little used to it with Abby. Abby went through not near that, Abby could already sit and do her treatments, she was almost 4. So, yeah, it took a lot of care that first year or so. And then therapy, just like with Down syndrome, she had physical therapy, occupational therapy, feeding therapy, speech. She's had it her whole life, of course, just to function as well as she does, but we made it through that first year. [Laughter]

Gerald: So, how much more complicated does it make it also, then with a diagnosis of Prader-Willis?

Janalen: It was very complicated. And the doctors weren't sure, you know, they were like- because she was so unique, they didn't know how it would affect. I think the hardest thing is that with the low muscle tone, it was so hard in the beginning. And even now, it's just so harder for her to clear her lungs, and to stay active with her lungs clear with that thick mucus. Obviously, Prader-Willis syndrome has been a positive with her weight. Prader-Willis syndrome, they tend to carry more weight, as they don't produce lean muscle mass. And that's been helpful for her, as we didn't have to struggle after the first couple years where it was hard for them to gain weight. Then, she gained weight, and that part has been fine. Actually, it's opposite, this one [Abby] has to have like 4,000 calories a day, or more, to maintain. And Katy can only have about 1,000. That makes it a little difficult in the house. Katy's been a rockstar and has been awesome about what she can eat and what others can't. So, this CF stuff, they are like we will do the CF stuff and treatments, and you are going to do this for that. And with Prader-Willis syndrome, you'll just do this for that, and we'll just see how it crosses over. But, I think it's made her lungs sicker. She's usually in the hospital a couple times a year for IV antibiotics. She has a central port now in her chest for IV antibiotics, the last several years. So, it just more care for her, takes a little more work.

Gerald: So then after the first two, you adopted.

Janalen: Yes, we adopted our first son.

Gerald: Okay.

Janalen: Katy was almost 5.

Gerald: From out of country?

Janalen: No.

Gerald: Domestic adoption?

Janalen: Domestic adoption. Before our oldest was born, we actually tried to adopt. It had taken many years to get pregnant, and so we had kind of gone through that process. And then ended up getting pregnant before we adopted. And so, when suddenly it felt like it was time to adopt, it was kind of a very quick decision, but it was a decision we'd made 7 years before. Just in our brain and our hearts that we knew that we would maybe adopt someday. His adoption happened very quickly, from the time we made the decision and really felt strongly we would adopt, we watched him be born 3 weeks later.

Gerald: Really?

Janalen: Yeah, so his was very quick.

Gerald: That is very quick. And your next child, who is 7, was biological.

Janalen: Yes, so the weekend we brought him home from the hospital, we found out we were pregnant. And had her 8 months later.

Gerald: I'll be darned.

Janalen: She does not have cystic fibrosis, just a carrier.

Gerald: A carrier of it, okay. Then you had another domestic adoption, that child is typical, doesn't have any issues. And then another adoption that was domestic, but it looks like that he has been diagnosed with a processing delay and selective mutism. Tell me about that. High anxiety? Visual perceptive delay? I mean I'm just looking at what Rachelle wrote here.

Rocky: I was like, "How did you know?"

[Laughter]

Rocky: Wow, that's impressive.

Gerald: Fear the Orange Socks...

Janalen and Rocky: Yeah

Gerald: We know all.

[Laughter]

Rocky: Exactly. Orange Socks rules. I wore pink today; I probably should have worn orange for you.

Gerald: You should have.

[Laughter]

Rocky: So, selective mutism is something that we didn't actually realize that he had. At home he's very aggressive in terms of playing with the kids, and just absolutely an extrovert. Occasionally, he'll do some wandering around the couch in the same patterns back and forth, which are called "stemming." Yep, occasionally some stemming behaviors, but we didn't think much of that, he was kind of growing out of most of that. And then the school teacher last year, about 2 months into school, asked if he ever spoke. And we were like, "What do you mean does he ever speak?"

"Well, at home does he talk?"

"We can't shut him up, what do you mean?"

"He talks?"

"Yeah, does he not talk in school?" 2 months, not one word, not one to his friends, no one. We were like, "Okay, that's not normal." So, we started pursuing trying to figure that out. We had him taken to a local place here that did a quick little series of tests on him, and decided that he was manifesting some ADHD. Which, I mean, I'm AD-double H-D, so I totally understand that. And then, this doesn't quite feel perfectly right, and so we did a little research. My wife, she's the queen of figuring this stuff out, did some research and found a selective mutism center. Which kind of matched all of the things he had, and so we contacted them and we actually ended up heading out to Philly to meet with a group out there. And they quickly were able to discern that they didn't believe it was selective mutism in terms of strictly not speaking because he didn't want to talk, but because he was a little bit delayed in how language reached his brain. We've been working now with them for, gosh, about 6 months, 7 months, and he is absolutely coming out of his shell. He now talks at school; he gets up front. I think what's to be learned from that is when you identify that a child has anything that seems off-normal, that quick response and proper care can mitigate those things fairly quickly. If attacked quickly, right? If you wait for a long time, and let that, like an old plasma screen, burn into the screen, it's hard to I think help those things. And so that's one of the things I think I've been grateful for my wife on, is that she is so willing to try to figure it out and act quickly on solving these problems.

Gerald: Obviously there's some sibling comparative things going on, and if Abby can eat 4,000 calories a day, and she [Katy] can eat 1,000, does that cause any...

Rocky: All sorts of issues. Typically not for Abby, because you know...

Gerald: Yeah.

Rocky: She's constantly wondering why other people are getting things she's not. It's hard sometimes for her to grasp that. Just because Prader-Willis, one of the manifestations is the hypothalamus doesn't regulate properly, which you probably already heard. So that means that she's always hungry. Like, literally, her mind says she's always hungry. So, when you're always hungry, and your family doesn't give you food, you see why the behaviors become a little bit-a lot of people you they see growing up a little sociopathic, but she's not done that at all, she's been great. And it's really been kind of a rigid schedule, that my wife keeps, probably why that's true.

Janalen: They call it food security; they try with kids. A lot of families with kids with Prader-Willis, they literally have to lock all the food away. So, everything has to be locked; the pantry, the fridge, in classrooms. I mean, if they know there's food somewhere, they're going to find it; if it's in the trashcan, anywhere.

Gerald: But you don't have to do that?

Janalen: We have not had to do that with her...

Gerald: That's awesome.

Janalen: She's been able to stay on a schedule, and she knows since she's going to eat breakfast and lunch, snack, dinner. She's okay. You know, she's sought food a few times. As she grows, she'll go through phases a little bit. We'll find things, or especially if we're out of town and it's a babysitter, or something like that. Once in a while, she'll try to get away with it. But she functions higher than we ever thought she would. She knows really well about the kinds of food she should eat, and what would be better. You know, if it's a birthday, she can have cake. [Laughter] If we as a family, it's a celebration, she can have some. We just do more portion control.

Rocky: And that's actually helped too, in the family. To be something that helps the kids understand that we don't all get treated equal, right? Because, a lot of times, kids will be like, "Well that's not fair, so and so gets this. Or so and so gets that." And it's easy to say, "Well, we agree that's not fair, I mean, it's also not fair for your sister. She has to deal with the things she has to deal with, and would you rather have that than not play on the iPad for the next hour?" I mean, so they could understand by just comparing and contrasting. That, "Okay, I guess life isn't always the same for everyone." And so, because of that, frankly, we can treat all the kids differently. Our oldest has no curfew, because she's shown through years, that she can be trusted and that she is responsible and that she's adult. And so that's been great. Now, are the next ones going to do that, I don't know. I'm not sure, we'll play that by ear.

Gerald: That's probably really smart because your kids are so different from another. And I think having that precedent is probably really important. You adopted him internationally from the Congo when he was 3, but he has two blood disorders. Did you know that at the time when you adopted him?

Rocky: We didn't know much.

Janalen: He was sick, I mean, he was sick in Africa. He just had malaria a lot of times on our first visit to see him. He was very sick, had an enlarged spleen. So, we assumed that he must have some sort of blood disorder, just with his enlarged spleen problem. And that actually was good because it gave us some leverage to put him in a foster home, out of the orphanage. And so, we were able to put him in a foster home our first visit, and he stayed there for, I guess, almost 18 months.

Rocky: Yeah, which is a better situation. The orphanage, I mean, they try to do the best they can. But no one there eats much more than once a day, and most of the time the food they do eat is not, you know, overly nutritious. And so, a lot of kids don't have a lot of nutrition going on. And then, they don't have the greatest place to sleep, I mean, if you look at the walls next to the beds when you came in, you'd see little red smears all over the walls by all the beds. And you're trying to figure out what those were, and then we asked somebody and they said, "Oh, those are the bed bugs." So, all the beds are infested. And so, they cause knotting and all these little wounds on their legs and their body because the bed bugs come out at night, and you know, chew on the kids. So, if they catch one, they'll smash it, you know, and the blood will go everywhere. Which is, of course, their blood. It leaves these little blood marks all over the walls. And so, we go in and try to help out when we can, and replace mattresses, and repaint the place to kind of clean it up. But, even when you replace the mattresses, the people that are there, everything is money to them. Even a little bit, they can sell, and they get money for. So, the people that ran the orphanage, they didn't really want to give up the old mattresses. Even though they were absolutely disgusting, and you know, they were bed-bug-ridden. And so, we had to work hard to get them out of the orphanage and gone to a different place, so they would never come back. We try to give these kids a better shot at no bed bugs for a while.

Gerald: And you went to Africa 7 times?

Rocky: Yeah, I believe that's right. Yeah, 7 times in about a year and a half.

Gerald: Tell me about that international adoption. Was that difficult, was it hard? Obviously, I mean 7 trips, you were there a lot.

Rocky: Yeah.

Gerald: Did you have to go 7 times?

Janalen: We chose to.

Rocky: There were a lot of things going on in the country, in terms of with their current political situation. Where once kids were adopted in the U.S., they didn't want to let them out. They didn't give them exit visas to leave, even though they had a visa to come into the U.S., and were technically completely adopted and recognized internationally by being adopted by an American family. They wouldn't let them out. So, we had to work hard to try and get the case pushed on as quickly as possible. And, to do that, it's much easier and more effective to do face to face, and working with people, and letting them remember that you're going to be back and that you care. And also, you know, helping. They need help with situations over there. Circumstances have put us in a place where we were in a position where we could help them, as well. Which was, I think, appreciated. And so, we tried to help the process go as smoothly and quickly as possible. And that was kind of a key part, really.

Janalen: At the same time, we got to, you know, spend time with him. All of those visits, we would go, and his foster family would bring him to us. And so, we would keep him those 4 or 5 days, you know, in the hotel, and play and swim and do things. Mostly him and I and Rocky would go do paperwork and different things. And we spent time with his foster family. And so, it made his transition home a lot easier. I think he transitioned home very well when he got home. Well, one thing that helped too, was we still had a lot of the kids here. We have a big family, with little kids his age, and he was used to that from his foster family, and the orphanage as well.

Rocky: And we FaceTimed while we were there. Our kids and him, so our kids got to see him repeatedly. And then, we'd also FaceTime with the foster family when we weren't there. So, we tried to keep top of mind with him as well. Just until he would be able to remember us. Because when we went there, the very first time, he was 2 years and 9-10 months. And so, when we finally ended up getting him, he was almost 4. And he'd seen us a number of times in person for days at a time. And then he'd also seen us via FaceTime, and also family. And so, he quickly assimilated into our family, and got along fabulously with the little kids.

Janalen: I used to make picture books, and I'd take them over, of the house, and all the kids again. So, we just tried to make things familiar for him. International adoption can be hard, and not all countries allow you to do that. Where the first time you're seeing the child, or they are seeing you, is when they are home the first time. Or you picked them up and brought them home. And so, we just wanted to facilitate a little bit easier transition for him home. And I think it helped a lot. And he was still so young, he learned English very quickly, very quickly. French was the language the foster family had taught him, and Lingala was his native tongue. And we would speak a little French to him and have people come speak French, and he just had zero interest. Just none. And he just assimilated very quickly, and has done very well. He is in Kindergarten, and just learning awesome. I mean, he's just doing great. He's a great kid.

Gerald: With all the kids, and all the different needs of the kids, sometimes the older children, or the other children in the family experience what's called the glass child syndrome. What that means is the parents are so concerned with the needs of the siblings, they look right through

the child. So thus, the glass child. And, I just wonder, how have you felt being the oldest of this tribe? Do you ever feel like you were, gosh, maybe your needs weren't met? Or that was all good? Just tell me about that a little bit.

Abby: Never. I've never felt like that ever. Yeah, my parents are very loving to everyone. Well, I don't think anybody has ever felt like in our family, personally. I have heard of situations like that in other families, and some of my friends are like, "How do your parents do it? I don't get it, my parents only have like three kids, and they don't ever have time for me." I don't know how they do it, but they're good at it.

Gerald: So, how do you think especially having siblings that have some needs, some special needs. Especially your youngest sibling has Down syndrome. All kinds of different needs. How do you think that this wonderful, big family has shaped you personally? What difference is that going to make? How are you different from your peers that might not have had the same experience?

Abby: I feel like I have a better view of what people are going through. And, like, I can get that everybody has, like, their own personal problems. And that everybody is different, and that not everyone is the same. And I feel like some of my other friends don't get that. They're just like, "Oh, their life is, like, totally okay. Like, they're fine." But, once you have something, you come to realize that everybody goes through stuff. And even though it's small, it could still be a big deal to them. So, I feel like you just have to be careful of other people and their feelings, and you can't just push that aside.

Gerald: Awesome. Well, you're awesome. You're a great kid, I can tell. So, your last daughter you adopted, Emma, from China. And how did that go? Was that an easier or harder process to adopt from China than from the Congo?

Janalen: A lot easier.

Rocky: Easier.

Gerald: It's easier.

Janalen: Mhm.

Rocky: Hate countries. There's a hate convention...

Gerald: Oh, yeah, yeah.

Rocky: Right? Those countries apparently, are legitimately way easier. Because they had to go through a lot of rigorous standards and set up to make the process smooth, and without the corruption that we saw in the Congo. So, what they said, you could count on. In terms of timelines and everything.

Janalen: And it happened. Paperwork was supposed to be done; it was done. When we showed up in country, everything was ready. Hers was a fast adoption.

Gerald: So, did you pick her out specifically?

Janalen: Yep, we found her on rainbowkids.org, and picked her out.

Gerald: You saw a picture of her?

Janalen: They had a few little videos.

Gerald: Okay, and why her?

Janalen: It just felt like she was supposed to be the one in our family.

Rocky: That kind of seems to be a theme throughout this whole thing. My wife, most of the time, has felt like we should do certain things. And so we have inspiration and revelation, and we think those things occur. And so we try to follow and do those things to the best of our ability, and we know that if we do that, everything will turn out all right.

Gerald: One of the most interesting things that I've noticed, that phenomenon of people recognizing their child if they see a photograph, if they have that. And I've interviewed Reece's Rainbow, and that's very common. I just wanted to see if it was my, maybe, because we are here in this part of the country...

Janalen: Right.

Gerald: No.

Janalen: No, I think God directs His children to be in the homes they need to be in, absolutely. And we felt that with our son from the Congo. We had felt this pull there for a while. We had friends adopting from that country, but at the same time we were adopting all those other kids, and thought we could never go through all that. Then, finally, like, "Okay, maybe show us some pictures of a few kids in the orphanage that aren't matched." And his picture, just right away I was like, "Wow." And showed Rocky, and he was like, "Hm." And we sat on his for a few months. It wasn't just right away because it felt impossible, his situation, because their country was really a mess. And after six months of sitting on it, we felt like we needed to just push forward and it would work out, and it did. It really did. But, so his was our first experience of kind of, the others were domestic and at birth. Birth moms picked us, but him and our baby, yeah, I mean, hers we just pulled up rainbowkids.org, and started going through little ones with Down syndrome in Asia. And just kept coming back to hers within two or three weeks' time, and thought, "Okay, I think we're supposed to move forward with her." And she just fits perfectly in this family. I mean, all kids with Down syndrome are the kindest, most loving,

sweetest. And she's been home almost a year. The end of February is when we went out last year, and she's just really acclimated, of course, so well. The kids just love her to death, they spoil her rotten. I tell people out of 8 kids, she's the easiest right now [laughter]. I mean, she has to have therapy, and it's been a long year of trying to help her to eat. And she'll get there, she'll get there. She'll eat and she'll walk, eventually. She's doing really well, and enjoying her time in therapy and stuff. I mean, she's just, she was a great addition to our sweet, little family.

Gerald: So, you have kids of all sizes, and shapes, and colors, and abilities. What do your neighbors think of this tribe here? [laughter] Church members? Do you get people looking at you going, because we did. When we would go out, we had people counting all the heads because we had...

Rocky: Or, they say to us, because a lot of them are the same age, or close to it...

Gerald: Yeah.

Janalen: And the same size.

Rocky: And the same size. People would say, "Oh, do you guys have a nursery?"

Gerald: Yeah.

Janalen: Daycare.

Rocky: Kind of, at our house.

Janalen: I get asked often, when I pull up in the big van, if I run a daycare. If I have a preschool. [laughter] "Oh no, they're all ours." We'll be in line to get on an airplane because we like to travel, and we travel with the kids. We take them all over, and they'll say, "Oh, what kind of a group is this?" And we'll say, "Oh, it's just a family."

Rocky: Family unit.

Gerald: You know we didn't adopt, but all of our bio kids, which is a shock that we would have that many because we started at 30. Our first child was born at 30. [laughter] One of the things that we noticed when we traveled; We went to Missouri, did some church historical sites, we had people doing the counting and all the stuff. "Are they all yours?" You know, that kind of thing. But one of the things that was not uncommon, we had multiple older people say, "I wish we would have had more children," and I thought, "Isn't that interesting." I was thinking that they would say, "Oh my gosh," whatever we would get, negative. We didn't. We got all positive from those that spoke to us, spoke about, "I just wish we would have had more, isn't this wonderful, this big tribe."

Rocky: When we first moved here, where we are now, we had two children. I thought we were done, so we were already discussing and talking about all the cool adventures we were going to have [laughter] when they left home. Because we'd still be young and vibrant, and could go out and tour the world. And then, I mean, in a three-year window we went from 2 to 8, almost. And, initially, there was some shock, and you know, I lost some of the dreams that I personally thought that I wanted. And then, as this has developed, I realized, yeah, I traded dreams. I traded what I thought I wanted, for what was actually best. And so, here we are. Right here, sitting here. And I think about it, and I'd take more children tomorrow.

Gerald: I guess, kind of wrapping up here, think about what has been your greatest challenges in trying to get this family that you currently have?

Rocky: For me, personally, it's been the evolutionary growth process of going from kind of a more selfish individual, who like I said before, had desires of doing things. Right? These things he wanted to do, to someone who was less prideful, hopefully. More humble, hopefully, right? And just enjoying the challenges that come. I mean you probably aren't going to see in the video, but earlier we had children in the background crying and screaming, and another one that refused to leave because they wanted more, you know, screen time. And to just recognize those things as just fun little events in life that we get to be part of, right? We get to be part of their learning and their growth. And to me the challenge has been putting away, frankly, the natural man, and trying to become a kinder, gentler soul.

Gerald: How about for you, Janalen?

Janalen: Oh, they're daily [laughter] the challenges. No, it's of course, it's a huge blessing and the challenges are different every time. Of course, having kids with special needs, and health problems, and all of those are some of the biggest challenges, I think. Thankfully, our oldest started us out with having her health problems. And so, we learned very quickly how to conquer a lot of those challenges that people do. As far as financially, health insurance, and medications. And some of those that would be a huge burden and stress on our family, if we hadn't figured out early how to navigate that system. And I've been extremely blessed with a husband who works very hard. He's such an amazing entrepreneur that provides very well. For that stress, as well as the financial stress of adopting all these kids, it's not cheap. Each one was very expensive, and we just laugh about it. We're like, "Well, we could have like two nice boats right now, or we could have all of our kids." And, definitely, it changes you as a person. I never thought growing up I would be a mom to this size of a family, this kind of a family. But, like Rocky, I would never change it. You know, I go to bed lots of nights like, "Okay, we just made it through another day." As they continue to grow, and we sit in bed sometimes and think of how it's going to be in ten years, when this kind of bunch that's the all same age together is our eldest's age, they're teenagers all at the same time. And how fun that's going to be. And we, like you, we got all these very late. And so, we are going to be quite old. And we had lots of sleepless nights in the beginning with all of them so close, and as teenagers, but we definitely wouldn't change it. I mean, the challenges are there.

Gerald: You know, I think for me, our house emptied all of the sudden. It's like I woke up one day and, they're all gone.

Janalen: Yeah.

Gerald: I have one left, you know, at home. And it's just, that's why when I look, I smile at your- because it's like, I remember. That's what our household was like, always this bedlam. We never got invited over to any body's house [laughter] just because. For dinner or for even a visit because we were just a footprint when we were there. That's all gone. I miss it, I miss it terribly, you know.

Janalen: We know that it will be like that with a big group. And that's a blessing that will never be empty because of our couple sweet, special needs girls. You know, we're hoping every day to just continue to instill love in them. That they will still be as close when they're married and gone, and together, and have a big extended family. As they continue to grow, they sure love each other. People stop us and talk to us. We went on a cruise this summer, and it was always so stressful in the dining hall with all of them, and being noisy and loud. But we actually had people stop and be like, "We admire what you do. These are great kids. You know this was really fun to watch." And, of course, as the mom I was so nervous every meal, all of those things. But people stop and ask, "How do your kids love each other so much?" We don't know, and we try, and they are close in age. We just hope that that continues as they grow.

Gerald: That's great. Thanks for taking the time to visit with me again to get this full, rich story. What a wonderful family you are, and great parents. I'm glad I know you.

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