An Orange Socks Story - Laurel and Jaron: 18P Deletion

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. In this episode I speak with Laurel and Jaron about their son, Shane, who has 18P deletion.

Gerald: Laurel and Jaron didn't find out about their son's disability until he was 4 years old, but the diagnosis wasn't a surprise.

Laurel: We assumed he was like any other kid until he started missing some mile markers. We started seeking early intervention, we would ask questions at the doctor and say, "So, do we need to have him tested for anything?" It was always, "No, at this point he's still doing very well, he's just behind, and he is receiving all of the services he'd have otherwise." It wasn't until this past year that we pursued it a little bit further. We spoke to the pediatrician who said, "I think the best person to have you see is Dr. Kurr she's a neurologist and a genetic specialist."

Gerald: When the doctor walked into the room the first thing she said was, "Shane doesn't look anything like you guys."

Laurel: And we kind of laughed about that, we felt like he looks exactly like his dad. But she was right in that he looks like us, but he also looks like other children with 18P Deletion. All it took was a simple blood test, it was a microarray that took all of 30 seconds to draw his blood. A week later we knew that the reason for some of his funny quirks, his little characteristics that we just thought were compilation of things that make up Shane. They are also things that come as symptoms of his deletion.

Gerald: Laurel and Jaron's reaction to finding out about Shane's diagnosis was similar to many parents.

Jaron: I was balling and I didn't even know why, because I already knew he had something. It was just good to finally have an answer, I didn't think differently of Shane. We waited four years and all of a sudden, we have this diagnosis. We thought, "What do we have to do? What does this mean with his life going forward?"

Gerald: Shane has a variety of symptoms related to 18P deletion.

Jaron: He has strabismus, which is a lazy eye, we got that corrected when he was 2. So far that surgery has held, so he doesn't have that anymore. He has mental delays, so even though he's five, he has a cognitive of a two-year-old. He has a little high blood pressure in his lungs, but nothing too much to worry about. Other things that are related to this disorder can be heart problems.

Laurel: The diagnosis for us means that now know what to watch for. The main thing we got from this is there are specialists we now keep up with every year, and so far, there is nothing noteworthy.

Gerald: Getting the diagnosis was helpful because Laurel could start educating herself. At the same time, it was a little sad knowing his condition was permanent and he would never, quote, "Catch up," unquote, to his typical peers.

Laurel: We were told to go to a website, and on it you can read through some of the things about the diagnosis and meet with a geneticist. We read through it and it's just naming off all of these little tiny characteristics that we already knew about Shane. It was kind of a relief, but also it provided some finality.

Gerald: I asked Laurel if she wished she had known sooner about Shane's diagnosis.

Laurel: I feel lucky that we didn't know, which seems kind of strange. I think with a lot of things it would be important to know right from the get go so that you can prepare for those medical health issues that could come, but in our case Shane's just a healthy kid. We got to know him and love him. The only difference is we found out what it was that was helping him to be the person that he is.

Gerald: For Laurel and Jaron, the most challenging part of Shane's disability is his difficulty communicating.

Jaron: You try to tell him something and he just stares at you kind of like, "What? You want me to do what? Like I don't understand what you want me to do." And then if he wants something, he doesn't know the word, or can't tell us so he just screams. So it's like, "I don't know what you want."

Gerald: Their favorite thing about Shane is his cheerful disposition and the way Shane has taught their family about what is truly important.

Jaron: He's just a happy kid, he just loves everybody. He's always hugging everybody. He'll hug strangers that you don't even know. You'll just be walking in the store and he'll just walk up and hug somebody, and you're like, "He's a hugger, you know, sorry." He brings a different kind of need to our family. It’s good for Savannah our oldest daughter because she’s the best big sister, she knows you got to take care of him.

Laurel: I had a neighbor ask yesterday, “Don’t you just hate how your kids bicker and they just try to push each other’s buttons?” And I just thought…

Jaron: So far, we don’t have that.

Laurel: Shane’s starting to come into that a little bit with Dallin, our one year old. Savannah is seven, Shane is five, and Dallin is one. Shane’s kind of learning that Dallin has wants and needs, and that it’s kind of fun to see the cause and effect. We have not really had that with Savannah, there’s been a big enough age difference so we could explain to her, and she’s such a bright kid that she just knows that although he is five, he’s not like other five-year-olds, and you can’t treat him the same way. But you always say, “Don’t treat him any different, but also do treat him different because they are different.” And he does have special needs, they have different needs than other kids, I mean everyone has special needs. It’s really cute to see Savannah as just this prime example of a big sister.

Jaron: She gets it.

Laurel: And it’s because of Shane that she has this compassion.

Gerald: Many parents go through a grieving process when they find out their child’s diagnosis.

Laurel: A cute mom on our tiny little Facebook group for families of children with 18P deletion, she came new to the group and said, “I just found out the baby I’m expecting has this.” She was kind of in this panicked state and worried about what to expect. I just remember feeling, “A baby, you’re having a baby! It’s going to be the best baby, and you won’t want to trade it.” Shane’s just always been this sweet little bundle of love, he just likes to hug and snuggle. I’ve always said if I had to duplicate any child, it would probably be Shane, but that doesn’t mean he’s my favorite, he’s just so sweet and good.

Gerald: Laurel and Jaron have been able to communicate with their extended family to help them meet Shane’s needs.

Laurel: We did have some difficulty where some cousins didn’t know how to include Shane. We did reach out to our siblings and just kind of explained what to expect of Shane. If he comes up around your neck from behind and has you in a choke hold, it’s really just a hug, so just hold really still and get that he really means well. A lot of them talked to their kids about it, and a couple of our nephews, in fact a seven-year-old one and a nine-year-old were like, “Shane doesn't have special needs, he's normal and we thought that was normal." We thought it was really cute that they didn't see that he was different. Shane's not social the way their kids are social, he doesn't talk and communicate the same way. But when you get going down a slide, he knows how to tell you that he's going to sit at the bottom and he wants you to come down and smash him off the end because he loves that high impact sensory stuff. He'll tell you he wants to wrestle and he wants to be physical like that. He's also really low muscle tone, so it's sometimes not received as wrestling, it's like what are you doing, leave me alone, you know. So, we kind of explained this to our siblings so that they could express to their kids how to better involve him, and we've seen a big change with family. So that's been really cool.

Gerald: Laurel and Jaron have advice for other parents if they receive the news that their child has 18P deletion

Jaron: Yeah, there's going to be issues, you're going to have to deal with some stuff, but they are your kid. You're just going to have to love them and treat them just like you would any other kid. Obviously get them the help that they would need and deserve, speech therapy, physical therapy and surgeries. We're lucky with Shane, he doesn't have a lot of the health issues that come along with 18P, but he is more severe with the cognitive and the mental part of it. There's other kids where cognitively they are almost normal, but they have all the heart surgeries and stuff like that. If you need support, get the support that you need. Even if that's through your family, your friends or doctors. Find doctors that are specialists because there's not a lot that know a ton about this.

Laurel: We don't know what to expect of Shane's future. We can only speculate based on the adults that we've met from the internet. Some of them work and have jobs and live independently, and some don't present with a lot of the symptoms and they are married and they have kids. That's probably why their kids have 18p deletion. Just because he has special needs, doesn't mean he's more likely to live with me till he's 42 than Savannah is, she could very well be the one that sticks around. You never know, you're going to have different circumstances with every kid.

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