An Orange Socks Story - Morgan and Rikki: NONO 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 Morgan and Rikki about their son, Landon. Landon has a deletion on his NONO Gene. A condition only shared with 9 other people in the world.

Gerald: Rikki talks about their first experience with Landon's disability.

Rikki: When he was born, we had no idea he had this condition. Not even an inkling that anything would be wrong. He was life-flighted at six weeks and we were told that he had only a 75% chance to live. If we left the hospital in less than 3 months, we would be lucky, and exceptionally lucky if we left with him not having had a heart transplant. If we did leave with him not having a heart transplant, he would for sure have one by the time he was one. We were out of the hospital in a week, and he still has not had a heart transplant, so miracles do happen.

Gerald: It wasn't until Landon was two and a half that he received his official diagnosis, which actually includes several other issues. Morgan's ability to pronounce his condition is helpful to me.

Morgan: One issue is a problem with his heart. It's called left ventricular noncompaction dilated cardiomyopathy, and it causes heart failure. On the right side of his heart, he's got Ebstein's Anomaly. His overwhelming diagnosis that covers everything is a deletion on his NONO Gene. It doesn't have an official name because he is the 10th kid to ever be diagnosed. This condition explains probably 9 out of his 10 diagnoses.

Gerald: Rikki and Morgan describe how they discovered the chromosome deletion.

Rikki: About every six weeks he would have something else that went wrong. We kept going to the hospital and they were trying to find the underlying cause. For a long time they couldn't. Primary Children's has an undiagnosed clinic, where if something is wrong with three or more systems, then you have a chance to be admitted to it.

Morgan: The exhume sequencing found his chromosome issues. This is when he got diagnosed. The undiagnosed disease program at Primary Children's gave us all of the medical information out there about this NONO deletion. There are a total of four articles. In two hours, I read all of the information that is available about what he has.

Gerald: Upon discovering that deletion was the source of all his serious conditions, they had mixed feelings.

Morgan: It was really relieving to have an explanation for everything. The down side to it is that I'm a carrier, and so is our daughter, Elise. So, the implications for future children is a little disheartening, it's just a scary thing knowing that I've passed this once, and I could potentially pass this to future children.

Rikki: He's our first kid, so we really didn't know what it was like to have a kid without any medical complexities. We didn't know any different at first, but it can make it easier for us. When he was first born, he vomited one to five times a day, every day. It was easy to get used to it because that was all we knew.

Gerald: Adjusting to this news, and their son's issues was a process.

Morgan: So, the first year was exceptionally challenging, he just had a lot of needs. We were living up in Idaho, so we really didn't have any resources for him, as far as a hospital or a specialist. So, we were driving down to Salt Lake very frequently to try and get him care and to try and get him someone who had any idea what was going on. Originally, we were told that he was going to need a heart transplant before he turned one, it was a guaranteed thing that carries a lot of fear. As far as physical care for a child, I think the hardest part was a year plus of a feeding tube. The therapy to try and wean him off of the feeding tube is not easy. For him, reaching any milestone is a lot more work than it is for a normal kid. It requires a lot more work and so we've been able to celebrate every little milestone, and a lot of milestones that most families and most kids don't even know happen, or even recognize, each time it is so exciting.

Rikki: For example, right now him eating these goldfish, yeah, we had to work at that to even get him to be willing to touch the goldfish.

Gerald: Morgan and Rikki pushed through several setbacks to make progress in tiny increments.

Rikki: With communications we've had a speech therapist working with him and done everything we can. The majority of the work has been Morgan since she is the one that's home with him the most. By teaching him words, he has baffled doctors and speech therapists. He does have a language regression, so he will wake up one morning and all of his words are gone. He can't say any words whatsoever.

Morgan: That he could say the day before.

Rikki: That would happen on a very regular basis, about every two to three months. So, we'd have to start from ground zero, trying to teach him again how to say momma, to say dada.

Morgan: I've taught him the word *more,* or the sign for *more* from ground zero probably six times. He will completely lose it like it was never there and that's tricky.

Rikki: My extended family just loves him. When they saw him walking, they were so excited.

Morgan: He didn't walk until he was almost three.

Rikki: And that was with a walker. Whenever my family would see a picture of it, they would tell me how wonderful and happy they were to see it. He quickly turned into one of the favorites because they just saw how happy he was walking.

Gerald: As with all parents of children with intellectual and developmental disabilities, the world doesn't stop, other challenges and trials still happen.

Morgan: When I was pregnant with him, my mom became really sick and she's dealing with terminal cancer right now. She really feels this deep connection with him, because they are both on similar journeys. They both really struggle medically. Because of that, she really feels this deep connection to him and loves him.

Gerald: Rikki talks about Landon's unique personality and abilities.

Rikki: He is the sweetest kid. Everyone he meets just wants to come and sit with him. Even with everything he's been through. He's had 7 teams of doctors at one time poking him, and prodding him at the hospital, while trying to figure out what was going on. He would just smile and laugh and is just happy as can be. He flirts with the nurses and he quickly becomes their favorite. He's just happy and makes everyone else around him happy.

Gerald: Having a network of support has been a lifeline for Morgan and Rikki.

Morgan: Find a really good friend who you can really confide in and just tell everything to. Another option is a Facebook group of parents who have similar struggles. Find those who can really support you in your journey, during really good days when you're really excited, and on those really hard days. There is a Facebook group, I think there are 5 of us who have this NONO deletion. We are each other's best resources. The doctors really can't do much for us because no one really knows about this diagnosis. So, the information we can provide each other is very important. We ask things like, "Does your son do this?" or "How have you worked through that issue?" It is really great for support, but we've also been able to ask medical questions like, "The doctors are stumped, what have your doctors done for this?"

Gerald: Morgan and Rikki have advice for other parents of children with similar issues.

Morgan: Don't lose hope, and keep the big picture in mind. There are a lot of hard days. If you can keep your goal in mind, it helps things a lot. Just take one day at a time. I feel like that maybe contradicts what I just said, but if you're trying to think of "How am I going to handle a month from now," or "What am I going to be doing 3 years from now?" it can be really overwhelming. Just focus on what you're dealing with today and the situations at hand today and tomorrow. Figure out what you're going to do tomorrow, that makes it manageable. Become knowledgeable in what you're dealing with. I find that if I can speak a little bit of doctor language, I feel like he gets better care. Become their biggest advocate, you know them better than anyone else. When he was in the NICU, I was told that the most valuable member of our team is you. The doctors know the medicines, the procedures, but you are the only one who knows him. That's important, get them what they need.

Rikki: Enjoy the happy times, even the little things. When dealing with his developmental delay, it was a long time between reaching some of those milestones. Just enjoy them and when they are happy, be happy with them. It's hard and life is rough. It's hard for you, but imagine being the toddler. He is the one who has everything going on with him. He has people poking and prodding him, if they can be happy, be happy with them.

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