An Orange Socks Story: Jessica and Jonathan – Two children with Hormone Growth Deficiency,
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.

Gerald: I had the pleasure of meeting with Jessica and Jonathan, who have two boys with unique medical conditions. I asked Jessica and Johnathan to explain their family dynamic. They have two sons, 6-year-old Trent and Jacob, who is 4. The boys both attend school and love to play sports and stay active. While both boys have a hormone deficiency disorder, Trent is more medically complex. Trent has been diagnosed with Autism Spectrum Disorder, vision impairments, a sensory processing disorder, developmental delays, and anxiety. Jessica has experienced loss in her family growing up, she had a brother pass away from holoprosencephaly. Her brother's passing greatly shaped her perspective and how she views her own boys. Both Jessica and Jonathan choose to see their son's abilities, and not focus on their disabilities. They are grateful that they are alive and in their families. When asked what a typical day looks like, Jessica says they make sure every day is planned out, so they can inform Trent on what is expected for the day. Trent does receive hormone therapy through injections and gets shots every day. Jacob has yet to start the hormone therapy, but it is anticipated that he will start soon. Interestingly, it took over 3 years for Trent to receive his diagnosis. After going to a lot of doctors, they found a complex-care pediatrician, and that was life changing. When they met with her the first time, the doctor had a pen and paper in hand and took very detailed notes. She asked questions and truly cared about his medical and behavioral history. After hearing all of Trent's symptoms, the doctor admitted that she did not know what Trent had. But she assembled a team and reached out to Jessica and Jonathan personally through phone calls. This team of doctors reached and eventually diagnosed Trent with a hormone deficiency disorder. She continues to manage Trent's case and has even started monitoring Jacob. She is also the one to diagnose Trent's other conditions. When they received other diagnoses, Jessica initially felt relief. She was relieved she no longer had to battle doctors for a diagnosis. But shortly after, she felt fear and grief. What Trent has is rare and Jessica doesn't know what to expect for the future. She shared how she was able to cope with the grief. Jessica said that for a long time she was so determined to find a way to help Trent, that she pushed the grief to the side. After Jessica allowed herself to feel the grief, she was able to move past it. The grief is still there and probably always will be, but she handles it better now. Johnathan explains how he feels about the situation 3 years after receiving the diagnosis. Johnathan feels very optimistic and feels Trent has a bright future. Jessica says she still fears the unknown. For example, 2 years ago, Trent had genetic testing done. And recently, the company's medical geneticist reran that DNA test and found something. They don't know yet, what it is, and are expecting a call any day to go over these findings. In the meantime, this fear of the unknown is very hard for Jessica to work through. The plus side is Jessica feels confident in her knowledge she has gained of the various diagnoses. She can talk to doctors and ask questions and be more involved in the conversations of his treatment. Even though Jessica and Jonathan have experienced hardships, they also have experience joys. For years Jessica was told that Trent would be held back in school. But one day, she received a picture of a certificate that said, "Trent is Kindergarten ready." For her that was huge and that helped Trent feel like a typical child. He was so proud of himself and was so happy. He had never experienced that before. Part of the joys they have experienced as a family is watching Trent and Jacob interact with extended family. Jessica says her dad has a very special relationship with the boys, they are like the 3 Musketeers. After the diagnosis, Jessica realized that her parents and sister were grieving too. They were grieving because Jessica was struggling with the emotionality of the situation, and how to continue moving forward. And they were grieving for the boys. Jessica's mom has always been supportive and loving. And Jessica's sister acts as a sounding board for Jessica. And importantly, they love the boys. Jessica's advice for parents in similar situations: she says to follow your instincts. She had a really difficult time in the beginning and wishes she would have pushed harder at first, instead of trusting what the medical professionals said. She says you are the expert on your child, continue to advocate for them, and ask questions and do your research. Jessica stresses, you are the number one most important person on your child's team. Keep that at the forefront of your mind. And doing that is what gets Jessica through. Jessica didn't stop there, once she decided that she was actually a critical part of Trent's care team, as opposed to an observer, she started challenging and asking more questions. She was able to decide what was best and worked with the doctors to get it. Jessica was able to advocate for Trent more, she was able to say what things were working and what things were not. Jessica became his voice, and she felt more empowered each time. That advocacy led Jessica to want to help other families that they can ask questions too. They don't have to come into a room and be a secondary person. They can come in and talk for their child. Advocacy turned into a big passion for Jessica, and she wanted to help other families. She founded an organization called Collaborative Corner for Exceptional Children. Collaborative Corner is a nonprofit organization and they have many specialists like speech and occupational therapists, behaviorists and education advocates at the ready to help families. They are also a sounding board for families, and there is no cost for their service. Jessica says first and foremost, she wants to give parents a place where they can go for acceptance and for answers.

Gerald: Tell me about your family, how many children do you have, ages and those things?

Jessica: Okay, well, we are a very close family, the four of us. We have two boys. I'm Jessica, and my husband Jonathan. And we have Joseph Trenton, he's our first son. He comes from-his name comes from a long line of Joseph's. My great grandfather, grandfather, my father, my brother, who passed away at birth from Holoprosencephaly, and then this Joseph. His name holds a lot of meaning for us. He is nicknamed Joe T by my dad, but he goes by Trent. So that's what we call him, Joe T or Trent. And Jacob is our second born. He just turned four. His middle name is Scott after his dad. Trent is in second grade; he is in the public-school system. He does really well in the public-school system, a lot of great accommodations. Jake is in a Pre-K class at a different school, and looking forward to going to his big brother's school hopefully next year.

Gerald: So, tell me about some of the special needs.

Jessica: So, both boys have Growth Hormone Deficiency. So that basically affects their pituitary gland, is what it is. They both work at different rates. They both have the same growth hormone deficiency diagnosis, but Trent's pituitary gland works at a rate of 30%, Jake's works at 70%. Trent is more severe. He's got a Rathke's cleft cyst that sits at the base of his pituitary gland. Once that was diagnosed, more diagnoses came for him. He is on the Autism Spectrum, he also has combined type ADHD, Vision Impairment, he has Sensory Processing Disorder, and some developmental delays. Really as he gets older, they are just adding on as he grows. This year we have added anxiety, but it is just a culmination of things, from the ASD and from the pituitary issues.

Gerald: Dad, let me ask you this, what did you think when you found out that you had kids that might have some special needs?

Jonathan: It was very similar to the reaction that my wife had. Denial, disbelief, fear and then with eventual, "Okay, what are we going to do, what do we need to do?" And so on. I think one of the things that really made it easier for me was my wife. My wife was absolutely amazing at research, advocating and really just finding as many answers and being as prepared as possible. Whenever we had any kind of doctors' appointment or visits, she really made a point of using that time very wisely and having almost an agenda as opposed to them dictating what the appointment was.

Gerald: So, you have experiences within your family.

Jessica: Yes.

Gerald: You also lost a child with a disability, was that helpful for you in your journey in accepting your reality as a parent of these two active little boys?

Jessica: Well it definitely made me look at things different and gave me a different perspective. Having the losses and then having the Holoprosencephaly in the family, made us thankful that we have both of them in our lives, obviously. We started to not look at their disabilities, but their abilities. It really changed our perspective and our mindset. And then obviously made us very appreciative because we have a 50% chance every time we reproduce of having a child with Holoprosencephaly. So the fact they are both here is a miracle to us. We realize this now, after we have had our losses. Our whole family realizes it after we lost my brother. So just having them here is everything to us.

Gerald: Wow, that is great. What is a typical day like for you guys?

Jessica: Well you can see the typical day is a lot of movement. A lot of redirection, a lot of communication, extra communication. With the Hormone Growth Disorder, they have to take injections for Hormone Growth Therapy. Jake has not started yet; he will be starting in January. Trent has been on them for several years now. It's a daily routine of injections for him. He will be on them for the rest of his life. They have some other dietary supplements and other things that they need, but we try to keep every day as planned out as we possibly can. That is what works best for Trent, which in turn works best for us as a family. So whatever we can do to let him know what to expect what is happening throughout the day. That seems to be the best. So, we kind of prepare them in the morning, we say, “This is what is happening.” They have the same routines for bedtime, they have the same routine throughout the day. We try to keep them in swimming and other sports at school. It’s just a typical day, we manage like a regular day.

Gerald: I appreciate that. You had an interesting story with diagnosis in the first place. First, dad, do you want to talk about that a little bit? Then we’ll have you finish up. Maybe not necessarily dwelling on what the doctors didn’t do, but what the doctor that got it right, did do right. That was such a powerful message to doctors out there for what they need to do to get it right, Jonathan?

Jonathan: Well, I’ll never forget that the very first phone call. The way that we found that first doctor that listened to Jessica is we went through a number of doctors early on in Trent’s life. Most of which dismissed it as normal, or you’re first time parents,

Jessica: Allergies.

Jonathan: Allergies. There was a number of things that were dismissed. So, she walked into this practice and was able to have a conversation. I remember it vividly. She called me pretty upset, saying that she spoke with a doctor and they said there is something genetically wrong with Trent. So, it startled me of course, and it kind of threw everything into perspective. Because now all of a sudden, a lot of things were starting to make sense. It wasn’t just normal. For the first few years I think I justified things in my head. Very much so as the doctors would say, “Oh it’s just normal,” or “You’re just first-time parents.” So again, it was Jessica who really had this feeling or inkling that is not normal, or that there was something else there. Thankfully, she fought for it and really went out seeking answers.

Gerald: What were your thoughts with this doctor and when she finally got the diagnosis of what was going on?

Jessica: So, this doctor was completely different. This doctor, she treated us like people instead of another patient. Our first appointment with her, she came into the room and she actually asked questions that she didn’t already know the answer to. So, she was very much about his health as a whole. She took detailed notes, she asked me questions that a lot of other questions other doctors hadn’t asked, and she really listened to every part of the background of his medical and his behavior. I had just spoken to her a bit during the first consultation about how we kept getting the run around on diagnoses like how doctors thought it was an allergy. So, I was going into this appointment thinking I’m probably going to get the same type of answer. So, she actually was different in a way that she immediately went to me as being the expert on my child. She looked at it through that perspective. So that changed the entire ball game. She was the first person to sit and actually listen instead of coming in with a preconceived notion of what this is just by looking at what I had filled out. She brought nothing in with her but a piece of paper and a pen, took notes and listened to my concerns. By the end she said, “You’re right.

There is something going on here. You're not a new crazy mom, it's not an allergy. These symptoms that you're describing are not typical. I'm going to find out what it is." And that she did. She went on a mission. She said, "I can't tell you what it is." Which is also a huge thing for a doctor to say. Typically, a doctor always tells us, "Oh this is exactly what this is," they know. She was very open about saying, "I need to do some research, I need to reach out to other doctors, let me see." So, she took quite a bit of notes, she got back with us and picked up the phone and called us. Which is also super rare, what doctor picks up the phone and calls you personally? So, she started to call us personally. She put together a team of different specialists that brought us to the growth hormone disorder diagnosis. After that, she kept managing us. She is a complex-care pediatrician, so she kept managing Trent's case. Every single time we would go in, she would say, "Okay, we have this component figured out, I think there is something else, I think we need to look down this avenue now." So, as we were going, she steered us into the direction every time of what the next diagnosis was and following through. She still follows through. She still picks up the phone and calls us. She has also kept an eye on Jake since he was born, she visited him in the hospital and did his first exam. She has been monitoring him and she manages Trent's case entirely and she has been life changing for us.

Gerald: So, what did you think when you finally got a diagnosis?

Jessica: Well when I finally got a diagnosis my first thought was relief, honestly, because I thought, "Okay, I'm not crazy, I have been battling this for almost three years." He was a very sick baby and toddler. He was always in and out of the hospital or the doctor's offices. I finally had a sense of relief, like there was an answer to what these problems were. So finally, I felt relief, but that relief was soon changed into grief, into sadness, and into a question of, "What's next, how can I help him, what do we do? This is rare, I've never heard of this before, this is rare, so what do we do?" So, I went into panic mode. I started researching as much as I could to become as educated as I possibly could be on it. I felt so much relief at first that turned into so many emotions after that. Every emotion, but fear, I would say, is the biggest because you don't know, it's the unknown.

Gerald: What things helped you through the grief process?

Jessica: There were a lot of things, I think. I pushed the grief aside for so long because I was so determined to figure out a way to help him. So, the grief was something that I pushed to the side. Once I was able to accept the diagnosis, and focus on his abilities instead of his disabilities, I was able to move on from the grief. It is still there, the grief is always going to be there. But I manage it a little bit differently now because I'm more educated on all of their different diagnoses. So, it will always be there, I think.

Gerald: How about you, what has been your journey coming to acceptance and getting through that. Did you have a grief process too?

Jonathan: Yes, I think the way I handle grief is I probably compartmentalize it a little bit more. I'm a little bit more analytical in personality, so it's not necessarily about the emotion I put forth, but it’s really about, “Okay, what is the next step.” So that is really kind of where we have been taking it at this point. Okay, so now we have this information and seeing what are we doing about it now. The biggest adjustment I’ve had through the journey is really the understanding that a diagnosis leads to potentially more diagnoses and the change of events or change of situations as Trent has grown. It is really saying, “okay, we have this information now, we are going to go down this path.” But also, in the back of my mind I’m thinking about, “Okay what piece of information is going to come to us next.”

Gerald: Okay so we may have already addressed this, but I’m going to ask again. Now that you’re, I assume, past that how do you feel now about the situation?

Jonathan: Very optimistic, a little bit more knowledgeable, and confident. Those are probably the best things I feel for all of it. I feel that Trent is going to have an amazing future, he’s going to do some amazing things. It’s not going to come necessarily easy or naturally, but that’s not going to change the outcome at all.

Gerald: Jessica, now that you have kind of worked through this, how are you feeling now?

Jessica: I’m still scared honestly. The fear of the unknown, it seems that there are so many different changes with his diagnosis and having Autism, you don’t really know what to expect. Each year as he grows, things are different, there’s different difficulties. I am more informed. I do feel more confident as well. I feel that I am able to handle the emotions about everything better, but I’m still scared. I’m still scared of the unknown. We spent so much time not having a diagnosis, that this is always going to impact me. I’ll never forget that feeling, and that feeling still lingers. I still think, “Is there another diagnosis coming?” We don’t know, we have done full genetic testing. We were just called recently that Trent’s genetic testing was re-ran and they found something this time. So, we will be going back to medical genetics in December. We don’t know what that holds or what that means, so the process of accepting one diagnosis and then moving on to the next and the fear of the unknown is just big for me. It’s always going to be there and always linger. I do feel like I’m able to have more conversations with the doctors now. Whereas before I was very quiet, and I did not ask enough questions. I feel like I ask enough questions now, and that I can talk to what his symptoms are more now. But again, we were just hit recently with a random phone call after two years from medical genetics that came and said, “Hey, the company reran his testing. They found something, and we are going to call you in December and discuss the findings.” That came out of nowhere. We thought we were on a good path, a good roll going and then this came out of nowhere, so you just never know. You never know.

Gerald: Sure. I think, unless there’s something about the challenges you want to talk about, why don’t you share a little bit about the joys that you’ve experienced?

Jessica: There are a lot of joys. Trent is unique, so unique. He is a mystery; you never quite know what you’re going to get. He keeps us on our toes. Both boys do. They are both the same and different, if that makes sense. They both have their own exceptionalities, but to me one of the biggest joys has been watching them succeed in certain areas that I know are extremely difficult for them. When we get these milestones that come across that are typical for other people, that are not typical for us, it is a huge joy. When Trent was in Pre-K, we were always told that he was going to be held back, or that he wasn't going to be able to be in the school system. I will never forget the day that I got a picture from his teacher, with a certification certificate that said, "Trent is kindergarten ready." That day was huge for me.

Gerald: Sure.

Jessica: That day made him feel like a typical child, and he had never had that before in any school setting. I'll never forget that day, he had the biggest smile on his face that you've ever seen. He was so proud of himself and I was so proud of him because he was so happy. He had never experienced that before.

Gerald: That's great.

Jessica: I'm sorry.

Gerald: No, that's all great.

Jessica: Sorry.

Gerald: No, no, no, it's perfect. Tell me about some of the joy's you've had as being dad.

Jonathan: The joys really just come from being proud and really for me just goes along with parenting in general. We're happy when he succeeds, we look for milestones and reassurances that us as parents are doing the right things. When I see Trent overcome an obstacle that didn't come naturally to him, it gives me great joy. I think about this summer we were determined to learn to ride a bike without training wheels. The first few go arounds; it was not very good. But as the summer progressed, we made the goal that we were going to practice and try. There was a lot of frustration on his part but now he can get out the bike and ride just like a lot of other kids. So, when I see those types of things, when I see that he is overcoming something that I know he from day one has struggled with, those are probably the most joyful moments. I think another one that probably hit me just as much, is Jessica spends a lot of time supporting Trent at school. And you know she sent this one picture with a group of three kids and Trent, and they all had their arms around each other and they are walking down the hall together. I know through our interactions and our social settings, that is not something that comes natural for him to have friends or make friends. I think that right there reassured us that we are doing the right things.

Gerald: So, tell me a little bit about the impact that these boys, and especially Trent, has had on your immediate family or friends?

Jessica: Our immediate family is very close, my dad, mom and sister we're basically joined at the hip. So, it impacted our immediate family very greatly. I think for my sister and my parents, they were watching their daughter struggle. They were watching me struggle emotionally and then they were watching me struggle with trying to find the best path for Trent. They watched me struggle emotionally when we started to see signs in Jake with the hormone grown disorder and then they were also grieving in their own ways about their grandchildren, or their nephew. They were getting hit twice as hard. Now that I'm a parent and I'm an aunt, I realize that it hits you hard. It hits you twice, it doesn't just hit you once. So, for them, they didn't want to do anything to make matters worse or add any more stresses. They were grieving in their own ways, but they are super supportive. They are best friends with the boys. My dad has a very special relationship with both boys and my mom has always been super supportive. My sister has always been a great sounding board for me, and has been personally very supportive to me as well. They love the boys, and they love them hard.

Gerald: So, what advice would you give to a mom out there that might be starting a journey similar to yours?

Jessica: The advice I would give you is to follow your instincts. I had a really difficult time. I wish I would have pushed harder in the beginning. I should have followed my instincts and pushed instead of saying, "okay," and trusted what a medical professional said, just because they were a medical professional. I would say follow your instincts. You are the expert on your child. Continue to advocate for them and ask questions. Do your research and just continue to be that expert on your child, and always know that you are the number one most important person on your child's team. Keeping that in the forefront of your mind really gets me through. That's the best I think I could ever give. Just always remain the number one player on your kids' team.

Gerald: Awesome, perfect. Tell me about your advocacy.

Jessica: So, once I decided I was part of the team instead of just somebody that was coming in and listening to the doctors, I started challenging and asking more questions and deciding this is what is best. And working with them together, I was able to advocate for him more. I was able to kind of say, "Hey, this is not working for us as a family, I don't think this is going to work for him." So, I really became his voice in that way. I felt a little bit more empowered each time. And that led to me wanting to help other families. To teach them that they can ask questions, and they don't have to come into the room and be a secondary person in the room. They can come in and be an expert on their child.

Gerald: And you started an organization.

Jessica: I did. I started Collaborative Corner for Exceptional Children. Advocacy turned into such a big passion for me because after I learned that I'm the expert on my child, I wanted to teach others that they are the expert on their child as well. I developed Collaborative Corner for Exceptional Children. It is a nonprofit organization and we help all families in need. We have a large panel of specialists and we do everything from education advocacy, speech therapy, occupational therapy, behavior, parent advocacy. We are a sounding board for a lot of families. We are also an organization that is free of cost to anyone in the community.

Gerald: What do you want to accomplish with this nonprofit organization?

Jessica: The main accomplishment that I wanted for Collaborative Corner was first and foremost was to give parents a place that they can go to for acceptance and answers. So initially I just wanted one centralized hub that people could get simple answers to questions they have. In their normal daily lives what they have to do is pick up the phone, leave a voicemail for a nurse, wait to hear to make a doctor's appointment. I wanted to take that step away. So, questions like speech progression, or their behavior. Families can email us directly and get those answers answered immediately. They don't have to wait, take off work or do anything outside of the ordinary email. We give a response immediately and we help them in any way that we can. So, I really wanted to take out the whole component of taking X, Y and Z before I can get the answer to one simple question. It was so difficult to get answers and I wanted to also offer people one area that had information on multiple different diagnoses. So, if your child, as we well know, after you get a diagnosis you may need speech therapy, they need occupational therapy, they need behavioral therapy. I wanted to put it all in one place so that way they didn't have to go to five different locations just to find out what they needed to do next or to find answers to their questions. We offer resources, national resources and local resources. We also work as education advocates. We work all together so we can be a one-stop-shop for the family. We can suggest where they can go for speech therapy, we can answer their questions, we can help them with an education plan. So, it really is just how to help a family as a whole. That has really been what we've been able to accomplish. It is working great for us right now.

Gerald: Super, awesome.

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