

## An Orange Socks Story – Jenna and Dan: Micronancia

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: Jenna and Dan welcomed me into their home for an Orange Socks interview. Their daughter, Ava, was diagnosed in utero with micronancia, or small chin, a symptom of a condition officially called Pierre Robin sequence or PRS. Ava's delightful, you will also hear her participating in the interview.

Gerald: Jenna, when did you find out your baby had some issues?

Jenna: We actually found out at the gender ultrasound. We went in, and Ava very quickly showed us she was a girl. We were super excited, dreaming about all of the pink stuff, and then I get back to work and receive a phone call from our OB. He tells me that he found micronancia on the ultrasound. micronancia is just a fancy term for small chin. Of course, I do the worst thing and googled micronancia, and basically saw worst case scenario pictures of babies with no chins. I got pretty scared. I did call my husband right away to let him know they were looking on the ultrasound for Pierre Robin sequence because my husband, Dan, had PRS as a baby, so they were looking for a small chin and obviously they found it. It wasn't until I googled Pierre Robin sequence to get the gist of what we were actually dealing with that I was able to kind of come to terms with it more.

Gerald: What are some of the consequences of this diagnosis? What are some of the potential difficulties?

Jenna: Pierre Robin sequence includes a recessed chin, a recessed tongue and a cleft palate, and all of those things together can lead to both breathing and feeding difficulties. Sometimes those babies come out and need a tracheotomy. Some need a jaw distraction where they have to surgically bring the jaw forward because the kid can't eat and they have difficulty breathing. Ava had something called a tongue lip adhesion because the chin and tongue were so far back that the tongue would often fall back and obstruct her airway, and she would start struggling to breathe. Quite frequently she couldn't lay on her back, she had to sleep on her side. We had to constantly reposition her because the tongue kept obstructing the airway. Ava is probably a more mild to moderate case, it can be much worse.

Gerald: So, Dan, you had an interaction with the doctors when they wanted to conduct a test. Do you want to tell me about that?

Dan: When we wanted to confirm the diagnosis, we went to a parinatologist who was able to initially confirm that it looked like she had Pierre Robin. The next thing they offered us was to do an amniocentesis on our daughter while she was in utero, and after asking them several times what we were going to do with this information

and not really getting a straight answer, they finally admitted that it maybe we would choose to discontinue the pregnancy depending on the results.

Gerald: This is a condition that you had, and you're obviously just fine.

Dan: Mostly.

Gerald: What have been some of the challenges that you've had? I mean, you obviously completed the pregnancy, and she was born. What were some of the issues right as she was born?

Jenna: It surprised me a little bit because I knew that Dan had come out not breathing and was blue. He had swallowed his tongue, and I was prepared that there were going to be some issues, so when she came out crying, I was overjoyed and relieved and had happy tears. I just kept saying over and over, "She's okay, she's okay, she's okay!" She ended up staying in the NICU that first night. They did find the cleft palate, and they wanted to monitor her breathing. They felt that if she was in a certain position, not laying on her back, that the breathing for Ava would be okay. It wasn't actually until a few weeks later that we began to see the implications of the breathing difficulties. She couldn't put on weight, she took a month to get back up to birth weight, and she was born pretty small. At a month old, she was still only 5 pounds 12 ounces and looked really sick. Finally, it was decided to do the tongue lip adhesion where they sew the bottom of the tongue inside the lower lip to hold the tongue forward so it can't obstruct the airway. For me, that was extremely difficult, because you're taking this little six-pound person and putting her through fairly major surgery. We were in the hospital almost two weeks getting through that, and there was a section of time where they had her attached to a breathing tube, and we really couldn't even touch her very much. It was probably one of the hardest things I've ever gone through.

Gerald: So how old is she now?

Jenna: She is nine and a half months right now.

Gerald: Okay, does she have any issues that you're concerned about?

Jenna: Not long-term issues. For example, she is about a month behind in her physical abilities because of the surgeries and the breathing difficulties.

Gerald: Sure.

Jenna: She had another surgery last week to remove the tongue lip adhesion. She has the cleft lip/palate repair surgery coming up, but other than that, she is a wonderfully smart, social little nugget here.

Dan: There are a couple of things that are more long-term that we'll be dealing with. One is because with a smaller lower jaw, there are often dental implications as they grow up, so braces may be medically necessary. The other thing that may also be necessary is speech therapy. I had speech therapy when I was growing up, and she may likely need some as well. Also, depending on how her hearing is, because she has tubes in her ears right now, that may impact speech development. Those are a couple of things that we are going to be dealing with ongoing.

Gerald: Maybe a little easier question instead of dwelling on some of the tough parts is what have been some of the joys? You obviously had this child, and you knew she had some issues similar to you, Dan, but she is a bright, beautiful little baby, so what are some of the joys that you've experienced with her?

Jenna: There are so many on a day-to-day basis.

Dan: Every time she smiles.

Jenna: Every time she smiles, she just kind of lights up a room. She likes to laugh a lot. That's what we call her monster voice. She reminds me all of the time to not dwell on the negative stuff. Because babies in general are so present right in the moment, they aren't thinking about this really hard thing they had to do last week, they're thinking about, "Oh, hey, mom, I'm hungry right now," or "hey, mom, you're really funny." There's a lot of strength and joy in that, and I sometimes feel like if she can handle all this, I have to be strong for her. I have to meet her with the strength she is showing us and just keep encouraging her, loving her and getting her through the really tough times. To do that, not dwell on poor me at all, because it's hard sometimes. I have lots of friends who have perfectly medically healthy babies, and it's very easy to get in this place where you feel like life is just unfair. It's always a spectrum, even with PRS kids. I think Ava is maybe a more moderate, mild case. It could it could always be worse, and probably could always be better, too. If I had gotten the typical baby, and I hate using words like that, but she wouldn't be Ava. There is something about her smile and her energy that is just incredible, just like a little ray of joy all the time.

Gerald: Dan, do you have anything you want to add?

Dan: There have been a lot of moments of joy, like when we first heard her laugh and when I hear her mimicking sounds that we make, that's a lot of fun. And in watching her as she is learning how to move her body in ways she hasn't done before and keep trying to do something that she hasn't done yet. After the first few times, I would start to get frustrated, and she just doesn't even compute that, so it's so cool to watch her do that stuff.

Gerald: What's been the impact that she has had on her extended family? Obviously, she hit home with your parents.

Dan: Yeah.

Gerald: Because they had you.

Dan: Yeah.

Gerald: How did that go?

Dan: I've been really impressed. Jenna's side of the family especially has really stepped up when they've been here, and they are super helpful.

Jenna: Oh, well, your side...

Dan: My parents are, of course, helpful as well, but they also have been there and they know that this is the drill, and this is what you guys are going to be going through. Your family is stepping in and being helpful and not really knowing in advance what it is that's happening.

Jenna: Yeah.

Dan: I know I've been really appreciative that they've been here and have come to visit as often as they have.

Jenna: I know at first it was kind of really overwhelming for my side of the family to the point where people at the first visit immediately after she was born were nervous to hold her. They had never experienced babies with breathing difficulties before and it's intimidating with someone so small. You don't want to do it wrong, you don't want to hurt her, and you don't want to upset her, whereas I think they expected to maybe be able to babysit to give us some time off but they're like well, you could go to a different section of the house, and we'll watch the baby.

Dan: Yeah.

Jenna: I think that was a shock for them, that they didn't expect that. That being said, once we had that first surgery that addressed the big breathing issues, they all just love on her so much; it's very fun.

Gerald: That's great. So, if I came to you with the news that gosh, we went to our 20-week check-up and we think she has this issue, what advice would you give me?

Jenna: I think there are things to address on the emotional side and things to address on the logical side. For the emotional side, I'd say it is okay to have a period of mourning, that your life is going to look different than you thought it was going to look.

Gerald: Well, what were the things that you felt you had to process right away?

Jenna: Because there are feeding difficulties between the small chin and the cleft palate, the babies can't create suction in their mouth, which means they cannot breastfeed, and as a first-time mom and someone who dreamed about being a mom, that hit me really hard. I really needed to process that loss, that I wouldn't be able to do that with Ava.

Gerald: What advice would you give me, Dan?

Dan: Be as supportive a spouse as you can. It's going to hit you at weird times how hard it is, and you are both the support system for each other.

Jenna: Does it affect you differently because you had PRS also?

Dan: Yeah, I think it does, because certain things that I see her going through make me afraid for her to have a similar experience, because there were parts of my experience that weren't very easy, and I wouldn't wish that on anybody. I always am trying to be watchful when she is going through something difficult, but I don't want her to go through what I went through. I just want something easier, something better for her, so that is something that I'm trying to be aware of, trying not to get triggered, you know what I mean?

Gerald: Sure.

Jenna: I would say on the logical side to just do a practical thing and keep a medical binder.

Dan: Oh, yeah.

Jenna: There are a ton of different doctors. Between speech specialists, GI and plastic surgeons, you're seeing a whole team of people, and if you are not her advocate and keeping everything straight, who is going to do it?

Gerald: Sure.

Jenna: We always have a medical binder that goes to every appointment.

Gerald: She has a condition that you obviously can relate to, Dan, because you had the same condition, so you can feel for what she is going through and for what she may go through. She's had medical procedures that are difficult so far, and she has some yet to go, so you are having to deal with issues that parents of typical children don't have to deal with. Last question, was it worth it?

Dan: Yes.

Jenna: Yes, I cannot remember what life pretty much was before.

Dan: Right.

Jenna: With Ava, it is both harder and better at the same time, and I think this experience has made me a better parent. I love harder and I appreciate more. Hi, are you hungry? The payoff is worth everything. There is a bittersweet taste sometimes, especially as you get closer to and also farther away from surgeries. There are so many times where I hold her because I know a surgery is coming up, and I want to keep this moment forever because, "You're safe right now, and I don't know what tomorrow will bring." I'm sure it will be fine, but I'm freaking out. Hi, you trying to say something? Oh, okay, I know we can get your bottle in a little while.

Gerald: Anything else that you want to say?

Jenna: Reach out to your communities. Orange Socks is a great resource because it connects people, and if you can find other people in a similar spot, it's going to be really helpful.

Gerald: Thank you both.

Jenna: Thank you so much.

Gerald: I've enjoyed meeting you both and meeting Ava. She is a doll. I've enjoyed our time together.