An Orange Socks Story – McKenzie: Diaphragmatic Hernia, Cystic Hygroma, and Renal Agenesis

Interviewed by: Gerald Nebeker, President of Orange Socks

Gerald: I am so glad McKenzie sat down with me for an Orange Socks interview about her two children. Her first child, Trevor, has Down syndrome. And hoping for a child without a disability to be a buddy and help to their son, they wanted to have another child. Unfortunately, this child, Maely, had diaphragmatic hernia, cystic hygroma, renal agenesis and other issues. Maely passed away one hour and six minutes after she was born. I appreciate McKenzie's honesty and learning her very tender story.

McKenzie: So Maely Grace, she was our second. We were so excited to find out we were pregnant with her because we felt that Trevor having a sibling would help him so much with his development. When he could see that a younger sibling was doing things that he was taking a while to do, it would motivate him to get going. We did the cell-free DNA testing at our first appointment because of Trevor. We wanted to be a little more prepared this time than last time, so we did that, and everything came back okay, showing no genetic issues, no Down syndrome, no Turner syndrome, or any of those other things, so we were feeling great. I went in for my 20-week anatomy scan at my doctor's office, and his ultrasound tech had a hard time with the images because there was not a lot of amniotic fluid and the baby was small. She just thought that maybe I ovulated on a little bit of a different date than I thought so that I was behind a bit from where we actually thought my due date was going to be. She told me to come back in a couple of weeks when the baby was a little bit bigger, and we'd be able to see more. We said, "Okay," and we weren't worried at all. The next day my doctor called and said, "I'm not too stressed, but I want you to go to a specialist at maternal fetal medicine, just to make sure everything really is okay. They look at babies all day and have a little bit more training than our technicians do, so I just want you to go in there." I did, and I wasn't worried about it. It was the exact same office that we had gone to with Trevor just a couple of years before, so I went by myself thinking that it wasn't going to be a big deal. What I thought was going to be a quick appointment, turned into a two-hour, horrible news appointment. As they were looking around, they saw that Maely had a lot of birth defects. At the time I didn't understand a lot of what they were saying to me. I didn't understand the vocabulary, but there were about 10 things on this list that were problems, and three of them were fatal. She had a diaphragmatic hernia, so her diaphragm didn't form all of the way, and it left a space, I think it was on her right side, for her liver to kind of float up into her chest cavity. Her liver was pushing her heart over, so her heart was out of place. She only had one kidney, and she also had a cystic hygroma on the back of her head and neck area. Any of those things by themselves are not good news, and all together they were really, really horrible news. And because they were all together along with some other more cosmetic issues, I guess you could say, they thought that it was a genetic thing. They were a little bit confused because I'd had a cell-free DNA test that had come back all right. They decided that I should probably have an amniocentesis test done because it’s a little more in-depth, and they hoped it could catch what was happening and see if the cell-free DNA test results were a false negative or something like that. A couple of days after that initial appointment, we went in for the amniocentesis and waited for those results. They came back showing no chromosomal issues. We were frustrated, because it’s not like we wanted her to have Turner's syndrome or Trisomy 13, or something else. At the same time, having a name to the diagnosis would have helped so much. We were just left with all of these abnormalities that they told us would either cause Maely to be stillborn or die very shortly after birth. The doctors talked to me quite a bit about terminating the pregnancy because there was just no viability for life, and they just didn't think it was a good idea for me emotionally and physically to carry her. Of course, there was no way I was going to terminate her. I wanted to carry her as long as possible. We didn't know exactly when things would happen. I am so glad I stuck with her as long as I could.

Gerald: How did you feel about this, because you already had a child with a disability? What was that like? Tell me a little about your first child.

McKenzie: Trevor will be two in March, and he has Down syndrome. When we got pregnant with him, we didn't even consider tests for Down syndrome or chromosomal issues because I was young. I thought those things happened more in older women. We just didn't really think about it. With Trevor, again at the 20-week scan, they saw that the ventricles in his brain were a little bit enlarged and had cerebral spinal fluid in them. My doctor told me I needed to go to maternal fetal medicine and have them look at it. The ventricles were very, very mildly enlarged, it was a mild ventriculomegaly. They were a millimeter over what the normal range for them was. So again, we weren't very worried. We went there, and the technicians looked around and everything looked good. We couldn't see his heart very well because he had his arms crossed over his chest, but everything else was okay. Then the doctor came in and said, "You know, it’s a very mild case of ventriculomegaly. It will most likely resolve itself on its own. We'll keep watching you to make sure it doesn't get worse or a lot bigger, but I just want you to know that this could be a soft marker for Down syndrome.” When it’s your first kid and you're 25 years old, when you hear the words Down syndrome at a doctor’s appointment, you freeze up, the world stops, and you're not quite sure if she really said Down syndrome or not. We were quite shocked, and she said, "What questions do you have for me?" And my husband didn't know what questions we should have. We didn't know about healthy developing babies and non-healthy babies. We had no idea. We went home that day and tried to process everything and think about what to do, because the doctor did mention that there were options. We could terminate the pregnancy, and that was totally okay because Down syndrome is a serious disability, and they would understand, but it was our choice. It didn't take us any time at all to decide we weren't going to terminate. Obviously, we continued on with Trevor's pregnancy. I decided to not even have more invasive testing, I didn't want an amniocentesis and I didn't want to do CVS because I felt calm about the whole thing. We felt worried, and we were scared because we didn't know what that meant. We knew very little about the details of Down syndrome. I had interacted with plenty of people with Down syndrome in my life, but I didn't know what it was like to raise a child with Down syndrome. We were a little bit worried, but we decided to just let things go, and as long as we could see that Trevor's heart was healthy, we would just try not to stress about it. I ended up having a fetal echocardiogram and Trevor's heart was fine, which was a big relief because many times, children with Down syndrome have heart problems and other serious anomalies that accompany it, but Trevor didn't so we felt great. I think initially finding out in that first appointment that he could have Down syndrome was really hard, that was our big grieving moment. I know that a lot of parents who have a child with Down syndrome are surprised with it at birth, and then at birth they have to go through that big shock and cope with that new diagnosis. We did that around the 20-week scan, so by the time Trevor was born, honestly, I wasn't even thinking about Down syndrome. It wasn't until I was in the recovery room after my C-section that the pediatrician came in with my husband and started talking about the initial exam he had done and that he thought there was about a 50/50 chance that Trevor could have Down syndrome. I was like, "Oh, yeah, I forgot this was maybe going to be an issue!" I'm so grateful for the way that it happened for us because we were able to have that time to really be upset before Trevor was born, so when he did come and ended up having Down syndrome, we were okay. It was still a little bit scary, he ended up being in the hospital for five weeks just because he was five weeks early and small. He had to learn to eat and breathe on his own, but other than that, it was okay.

Gerald: You already had a child with a disability, a kid with Down syndrome, so you had high expectations for your second child, and then you found out about all of this stuff that was going on, and the doctors told you that it would be fatal. Is that right?

McKenzie: Yes.

Gerald: What were your thoughts?

McKenzie. At Maely's appointment at maternal fetal medicine. I was by myself and I held it together pretty well while I was there. I don't think I started crying until the last 10 minutes because I was just in shock. When I got home, my husband was still at work, but my sister and my mom were there, and when I walked in the door and saw them, I was just sobbing and sobbing because again, you don't go to an appointment expecting to hear that you'll be lucky if your baby is born alive. I could barely even speak to my mom and my sister, but one of the things I did say was just that I was so upset and confused and angry because I didn't understand how there were families that could have four, six, ten kids who were perfectly healthy, and I couldn't even have two who seemingly were not okay. That was so frustrating because like I'd mentioned before, we'd had so many hopes and dreams for what Maely's and Trevor's relationship would be like, and to realize that wasn't going to happen was hard. I remember thinking back to when we found out about Trevor's diagnosis a couple years before, and I went home that night and was talking to my mom about his possibly having Down syndrome, and I said to her, "Ugh, I'm glad his heart is okay, and worst-case scenario, he'll have Down syndrome," and I stopped myself and said, "Whoa, whoa, whoa, Down syndrome is not the worst-case scenario, because at least I'm still going to have a baby." Fast-forward two years to experiencing all of these things with Maely, and I am living that worst-case scenario where Down syndrome or some other diagnosis is not the worst thing in the world, and realizing that the worst thing in the world is that your baby is not going to live. And at that point, wishing she had Down syndrome or something that maybe would cause her to not have a typical life, but that you'd still get to raise her and that she'd still get to be with you. It was hard. We were confused about why Trevor's random Down syndrome and Maely's seemingly random problems were in our family. We're still going through this questioning process. We're still not quite sure what caused all of Maely's problems. We had a full autopsy done after she passed away, and we're still waiting for those results to come back, so hopefully they'll have some answers. To be quite honest, we don't think they will, but then we'll go from there.

Gerald: So, with this second pregnancy, you were encouraged by the doctors to abort the baby. Why did you decide to keep the baby?

McKenzie: I think a lot of it has to do with our religious views. We're Christian, and we don't believe in abortion. But I would like to think that even if I didn't have those religious views, that my personal moral and values would lead me to keep the child. I just know that life is sacred, and it's not something that we get to decide when to end. I didn't once ever think that it would be a good idea to terminate Maely's pregnancy or Trevor's pregnancy, but especially Maely's, even though her problems were so much more severe than Trevor's. Trevor really didn't have any problems because his mild ventriculomegaly did go away. His Down syndrome was the only problem, but it was hard as a mom, wondering if Maely was suffering or not with all of her problems. She only had one kidney, which was the reason she didn't have very much amniotic fluid as it wasn't going through her body like it should. That whole system, that whole process, wasn't functioning, and it was hard having the faith and hoping that she just was okay and that she wasn't suffering, that as long as her heart was beating, she was all right. Even constantly, always praying that she was okay, there was still no way I was ever going to terminate.

Gerald: How long did she live after she was born?

McKenzie: Maely was born at 12:34 pm on a Friday afternoon. The pediatrician was there when she was born and was constantly checking every few minutes for a heartbeat. We really did not expect her to live at all and were hoping for two minutes after she was born, but she lived an hour and six minutes, so just a little after 1 pm, our pediatrician called her time of death. It was very hard, but it was also peaceful. We were so grateful that we got that much time with her because we weren't expecting to have more than a few minutes, so we felt truly like that was a miracle.

Gerald: What did you do during that time? Did you hold her? Did you have family around and all of that?

McKenzie: I had a C-section because I hoped that Maely would survive that birth better. I was afraid that if I had a vaginal delivery, it might be a little bit too much stress on her already fragile body, and that she wouldn't survive that. Like I said, she was born alive, my husband was with me, and the hospital was so nice and extremely accommodating because of our situation. Normally, you're not allowed to have anyone in the OR, but they let my sister be there. She's actually a labor and delivery nurse at that hospital, so they let her be there, too, and she took some pictures for us and a few videos, and that was amazing. We cherish those now. My husband and I stayed in the OR with Maely while they continued to stitch me up, and then when they were done, they asked me if I wanted to stay in the OR, go to the recovery room, or go to my postpartum room where my mom and my husband's parents were waiting with Trevor. We decided that we wanted to go the recovery room and spend as much time with her as we could. We went in there and had my sister go and grab Trevor and bring him into the recovery room, and that was probably one of the most special moments of my life. Getting to have that time as a family of four was so precious, and we were so grateful that we had it. We spent a few minutes with Trevor, my husband had him in his arms and helped him to touch Maely and stroke her soft fuzzy hair, and we took a lot of pictures and a lot of videos and just really tried to soak in that time that we had as a family. I'm not exactly sure if Trevor was in the room when

Maely was gone or not, but after she had passed away, we went back to my postpartum room, and that's when my husband’s parents and my mom got to hold her. We didn't have any extended family or even immediate family see her while she was alive, but we did exactly what we wanted to do because we didn’t want to have any regrets, and we're so grateful we did it the way that we did because we got a lot of really precious time with her.

Gerald: If I were in your situation, knowing what you know now, what advice would you give me?

McKenzie: Oh, my goodness! That's a loaded question. I would tell you that being a parent is the best thing that could ever happen in your life.

Gerald: Even if your child only lives an hour and how many minutes?

McKenzie: Six minutes

Gerald: An hour and six minutes?

McKenzie: Absolutely. I think that I would tell you that it was going to be hard. You personally will be tested, your marriage will be tested and you'll go through a lot of ups and downs, but just keep in mind what your end goal is, which for me was to have my baby in my arms. I didn't care how that was, I just wanted to be able to hold her and have her. If you can keep that end goal in mind, I think it’s all worth it. I mean, we were extremely lucky and really blessed that Maely was born alive and that we had her for a little over an hour. We would have felt grateful if we had her for only five minutes. So many parents don't get that opportunity to have their living, breathing child with them for any time at all, but I think even in the case of a stillbirth, you know you're a mom and you know you're a dad. You know that’s your child. Newborns look a little bit funny right when they're born, but you can still pick out the traits that your baby has that are yours or your husband’s. I guess I would just say, “Don't lose hope.” There's of course, going to be some sadness, but there will be so much happiness too, and you will create memories that I truly think will last a lifetime. As far as Trevor, Down syndrome is not scary. Our situation is pretty unique, contrasting Down syndrome with things that can be so much worse, because I think in life it’s easy to get caught up in what we think our problems are, and then we might kind of beat up ourselves and think, "Oh, it could be so much worse." Of course, things could always be worse. I don't think it’s healthy to invalidate your frustrations. I think it’s important to experience those emotions and really feel them, but at the same time, I don’t think it’s good to wallow in them. I'm grateful we were able to get over that bump of finding out that Trevor had Down syndrome, and yes, it could have been worse, and it was worse with Maely. I think that really helped us to appreciate Down syndrome, which might sound funny, but we really do. It's not scary. We are very fortunate in that Trevor doesn't have any of the health problems, but it’s still different. We have a lot of therapy. We still have more doctors’ appointments than we probably would if he was a typically developing child, but being a parent is a joy no matter what your experience is. It’s hard, but everyone's parenting experience is hard. It’s just harder for different reasons.