

An Orange Socks Story - Kassy and Darren: 7Q 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. Having a child with significant disabilities is both a blessing and a challenge. Especially if that child has a rare condition. Such is the case with Kassy and Darren. Their son Kenai is one of few in the world that has been diagnosed with 7Q deletion. I know you're going to enjoy learning their story.

Gerald: Kassy and Darren have named all of their children with K names. One day Kassy told Darren some interesting news.

Kassy: I had a dream that I was washing a little boy's hair in the sink and his name was Kenai. I woke up and I said, "I had a dream that I had a little boy and his name was Kenai." And we were like, "Oh my gosh, we never thought of that it's perfect." Two-three months later I was pregnant.

Gerald: There was no indication that Kenai, named after a peninsula in Alaska, would be born with a disability.

Kassy: He was born five weeks early. He was in the three-pound range. When he was less than 24 hours old, one of the staff in the NICU told me that there was something majorly wrong with him and motioned to her head. By day five of life, they told us it was a deletion on the seventh chromosome, there are about 34 reported cases that are similar, but not exact to his.

Gerald: Because the diagnosis was so rare, the doctors could only guess what would happen next.

Kassy: They didn't really know what he would do, if he'd smile or anything. He would kind of be a vegetable, and he was so tiny when we got his diagnosis. I Googled it, and all of the results were bad. All of the cases were bad and scary, and it took me a while to just breathe and not try to search on who he would be, and just watch him develop. That was kind of a hard hump to get over. So, he was in the NICU for nine weeks, he was life-flighted up to Primary, and before he came back, the doctor called and said, "Do you want me to just put a button in him, a G-tube?" And I said I just want to wait and see if he can do it on his own, we'll deal with it. He was then on a NG. No doctors really thought he'd ever feed by mouth, but he is. There are things that they'll do that the medical field will tell you they will never be able to do. He came home on three different types of monitor machines.

Gerald: Since his birth, Kenai has had to have many medical interventions, including open heart surgery. He is now 18 months old, and after receiving Kenai's diagnosis, Kassy and Darren have experienced many different emotions. They also experienced people close to them experience the evolving emotions that come when a baby is diagnosed with a disability.

Darren: My family is kind of dramatic. When we first brought the news to them, a lot of them were really taken back and automatically sent things into worst-case scenarios, and they kind of connect their own dots.

Kassy: Their initial reaction would be, "I'm so sorry," and I had to just say, "Don't say sorry, we're still excited and we still just had a baby and we still love him so much."

Darren: Maybe they were scared for us, but we never felt that way, as they've seen Kassy show what life is like with this awesome kid. Our whole family has come together and it's not as scary for them.

Kassy: Watching our other kids with him has been so super cool. They've always been really sensitive to each other. I know that having a kid with different needs can be hard. It can be a learning curve and it can be hard on a marriage. He seemed to strengthen everything. They've been so great with him, they're really in tune with his needs and what's been going on. It's been really awesome to see the family dynamic.

Gerald: As the family came to terms with Kenai's diagnosis, they lovingly reached out to assist Kassy with the everyday rigors of caring for Kenai.

Kassy: He's harder to hold due to his hypertonia, he's harder to feed because he has a cleft in his soft palate and it's not repaired yet.

Darren: A lot of our extended family has babysat and taken the kids, and that's given Kassy some time. She literally has zero time to do stuff due to the machines and everything that came into our reality.

Gerald: Kassy has some advice for parents when they receive a diagnosis.

Kassy: Do not Google anything ever. Don't take your doctors word for it because they don't know everything, they can predict all they want, but no one's going to tell you what your baby is going to do until your baby tells you what they are capable of. You just need to wait. It's hard to accept, but you need to trust the process and trust your journey.

Gerald: Kassy and Darren have consciously decided to live in faith rather than in fear. Instead of comparing their son to other children, since Kenai's diagnosis is so rare, Kassy says they wait for Kenai to show them what he can do. Great advice.

Kassy: I kind of thought if I met someone else that had a daughter that was the same age as mine, both of them don't have a deletion, don't have a diagnosis and their daughter has cancer, I'm not going to automatically think my daughter is going to get cancer now.

Gerald: Darren echoes Kassy's choice to see things in a positive light.

Darren: Positivity is a big deal for us. You really attract what you think about, that's why I've commented so much about him being this positive entity in our home. There's a lot of

positive stuff that can come from this, I would just say concentrate and focus 100% on all of the positive things and build off that.

Kassy: I don't ever really say that he's disabled, I say that he's differently abled. He's pretty awesome I don't want to put limits on him.

Gerald: Sure.

Darren: We felt pretty blessed. He's always had this aura, this energy about him. This kid is massively positive all the time. He's just got this different vibe that lights me up every time I'm around him.

Thank you for listening to this episode. Orange Socks is an initiative of Rise Incorporated, a nonprofit organization dedicated to supporting and advocating for people with disabilities. Follow Orange Socks on Facebook and Instagram, and visit our website orangesocks.org for more stories and to find national and local resources to help parents of children with disabilities.