An Orange Socks Story - Cathy and Brian: Down Syndrome

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: So, Cathy, your son Cole is your oldest. He has Down syndrome. When did you find out that he had Down syndrome?

Cathy: We found out that Cole had Down syndrome, after he was born. I had gone in for my eight-month ultrasound, and during that ultrasound they had spotted some blockage in the intestines, and that's called duodenal atresia. Which meant that we were going to be facing surgery immediately after birth. In the course of preparing us for that surgery one of the doctors has said, "That you should be aware that one out of three babies born with this blockage has Down syndrome." So, we knew that our odds had gone up pretty dramatically, I was an older mom and they had done a few tests, but they hadn't detected anything up until that point.

Gerald: Brian, what were your thoughts when you found out you had a child with Down syndrome?

Brian: It was pretty difficult, it was tough. The doctor's lay out a lot of things, and to be honest with you, it was very difficult. We were married later in life; here we have our first born and we are just excited for him, and then to get that diagnosis was very tough.

Gerald: Yeah, I remember for me, just as a personal note that when our daughter was born I cried the entire night, and I'm pretty sure it took me about two years to finally get my head around it. It's a tough deal.

Cathy: Yes, it was very difficult at the beginning even to say the words out loud as you're telling your family and your friends. I remember wondering if I'd ever be able to talk about it without crying.

Gerald: What's interesting for me, I thought it was somewhat a matter of arrogance. "How can I, Gerald Nebeker, father this child with Down syndrome?" I did this for a living, I supported people with disabilities and that almost made it worse. So, I hear ya. What did people say around you? Your family, friend's, church members, when you told them you had a child with a disability?

Cathy: I remember a friend of mine saying, "This is a gift from God," and in that moment, I wasn't ready to receive that gift. I remember Brian's sister-in-law saying, "You know, there are some things in life that you just have to go through, you can't go over it, can't go under it, you just have to go through it." I appreciated that, that encouragement of just take it one day at a time.

Gerald: How long did it take you to be able to talk about it with joy?

Brian: It took me a few years. When Cole was born, I felt a sense of responsibility, a sense of duty to raise this child the best I could, but I viewed it as a project. I had a responsibility and a project with Cole. But as time, and I mean about five or six years later, I started to see Cole's personality. The person that he is starting to come through and that my view really started to shift from a responsibility, to really loving Cole for who he is. I'm not sure that I've made that swing 100 percent, but we are a long way in the right direction.

Gerald: How did you adjust to your new reality? What did you do to try to deal with the grief?

Cathy: It was extremely helpful to talk to other people who had been through the same situation. In my position in congress, I had a lot of people, hundreds of people that were reaching out across the country and even other countries around the world, with emails, and cards and wanting to be encouraging. Just notes that I cherish to this day. That meant a lot, and they wanted me to know, and us to know that it was going to be a positive. That we were going to find a lot of joy in our son, and it's very true. So that was amazing, and then other people who came to meet with us and we reached out to others, it meant a lot to be able to talk to people who understood, who had been there, who had experienced the same feelings and emotions and had gotten to a very positive place.

Gerald: That's great! While you're on the topic, what are your joys that you've experienced with Cole?

Cathy: For me, I feel like Cole has taken some blinders off of my eyes. I see every person very differently, and it's the difference between having head knowledge, to now a heart knowledge. It gives me the ability to see the value and potential of every life, and even one that is different from anything I ever imagined. Having a son with Down syndrome has been very much a positive. We celebrate every success, every developmental success, every goal he scores. There is just a lot more joy in watching him reach his full potential.

Gerald: What's been the hardest thing so far?

Brian: I would say culturally we have a track that our children run on, grade school, athletics, and most typical kids fit into this track. I think the most difficult thing for me with Cole was realizing that Cole is on his own trajectory. I keep wanting to compare Cole's trajectory with a typical trajectory, but they are different, and so we don't have a lot of milestones with my son's trajectory. I'm always wanting to find out if he is being pushed too hard, not being pushed enough, is this appropriate for him, but I think Cole is more typical than different. You never want to underestimate him, he'll surprise you.

Cathy: I also think that Cole wrestles with that. Cole wants to be like the other kids and he wants to play basketball with the other kids. He's really good, but he's not quite as fast or quick as the other ones. He wants to be seen just like the other kids, he's very competitive. So, I think that is a big challenge for him too.

Gerald: So, Brian, tell me about your typical day.

Brian: Well, I would say Cole's typical day is typical of any fifth grader. We are up in the morning, he does some school work, he eats breakfast and gets dressed, brushes his teeth. We walk to school, and pick him up after school. He is outside playing with his sisters. He'll have a snack and dinner, then homework.

Gerald: Just like any other kid. So, Cathy, after Cole was born were you hesitant to have other children?

Cathy: We gave that some thought. The odds of having a second child with Down syndrome are pretty slim. I believe it is one percent more than the odds in general. I had met a couple of families who had more than one child with Down syndrome. I've met families who have adopted a number of babies and kids with Down syndrome. So, I had seen the multiples, and it certainly was in the back of our minds, but we always wanted more children so we decided to go for it. We decided we were ready to take on whatever may happen.

Gerald: So, you both are amazing people. Brian you are retired after 26 years as a naval commander, and Cathy, you are an eight-term member of the House of Representatives. That is amazing. You're from the great state of Washington. Thank you both for your service to our country, first and foremost, but with all of that, how do you balance the busy demands of life and three young children?

Cathy: Brian makes that possible for me, to serve in congress. He did have an exceptional career in the Navy. I met him after he had retired from the Navy and when we married and started having a family, he's sacrificed a lot to be at home with the kids. He says it's harder than anything he ever did in the Navy.

Gerald: [laughter]

Cathy: Yet he does that to make it possible for us to do what we're doing.

Gerald: Great, Brian, do you want to add to that?

Brian: Life is life, everybody has things going on. You make it work, and I think things have worked out well. It's certainly challenging.

Gerald: So, I assume that having a child with a disability has shaped both of your advocacies. Cathy, you have a full resume of accomplishments in the House. I was reading about so many of them, but for seven years you served as the Chair for the Republican Conference, and most recently, the Republican Representative to the United Nations. You've sponsored and passed several key bills that positively affect people with disabilities. The Steve Gleason Act, Steve Gleason Enduring Voices Act, The Able Act, The Able to Work Act, The Financial Planning Acts. One bill that's recent that I'm interested in is the Competitive Employment Act. We talked about that a little bit before, what do you hope to accomplish with that bill?

Cathy: My hope is to continue to move society to see the ability that every person has. They may have a disability, but to really focus on the ability and to focus on what that individual can offer. Especially at a time when we have a booming economy, we have record unemployment, a 50-year low of unemployment. This is the best time ever to look at "How do we really open that door for competitive work for those with disabilities?" We have still a lot that are making sub-minimum wage. That means that they are in positions where they are not being paid minimum wage. They may be there for the rest of their lives. So, the goal of this legislation is to phase out that sub-minimum wage job, and move these individuals into minimum wage positions. Do it over a period of time, offer support. There is a lot more organizations now that are focused on really coming alongside those individuals who have disabilities and helping them identify what their talent is, what their skills are, maybe giving them an education and training so they can get into employment. Organizations that are working with individuals with disabilities and employers. Whether they are for-profit, or nonprofit or government entities, they are really helping to bridge this divide. So, this legislation is one that I hope Congress will pass, and that we will embrace as a country ensuring that every person gets that minimum wage no matter what the work is that they are doing.

Gerald: Awesome, that is just awesome. What impact have you seen, or hope for in the lives of your two daughters?

Cathy: Cole has two younger sisters. My hope is that they are going to be fierce champions for everyone, and those with disabilities, having grown up in the same household and see the positive impact that he has. They love their brother. They enjoy playing with him and they are all very competitive. My hope is that they continue to be a fierce defender and champion for him and so many others who have disabilities.

Gerald: You know, it's interesting, I've interviewed a lot of families. A lot of times like with ours, the person with the disability is the younger and some after. But a lot of times I've interviewed them when they are a little older than your kids and everything you have said is true. 100 percent of the time, I have never met a family that had other children where the children were not advocates, and that they were changed profoundly because of that sibling. So, I think your dream will come true, guaranteed. Last question, I'll ask it of both of you, what advice would you give to a couple who just found out either in utero or after, that they have a child with a disability and Down syndrome specifically?

Brian: I would say that the journey is going to be a little different, but it is going to be a good journey, a positive journey. We have nothing to fear but fear itself. There are a lot of things out there that you're told that can give you a lot of concern, but you have a beautiful young child. They have a bright future, and just invest in it just like you would any child. You will see wonderful fruits and a wonderful relationship that is positive. That is what I would say. It’s different, you’re outside that normal track, but it is a different path and experience, but it is a positive and good experience.

Gerald: Cathy what would you have to say?

Cathy: I think that it’s the fear of the unknown that is overwhelming in that moment. To go talk to other people, don’t make an isolated decision. Do some research, educate yourself. I remember when we got the news about Cole, that so much of it was focused on the negative. It was focused on health issues that he may have, or the challenges that he may have, rather than being told what the potential was. I fear that so many when they receive a diagnosis, whatever that may be, that so much of the focus is either on the unknown or challenges versus what is a very positive potential also. Cole has exceeded all expectations. I’ve learned not to put any limits on him. He’s an amazing kid, he’s very personable, he’s very active, he loves to make you laugh. He takes joy in making you laugh. Sometimes it’s a little corny, but we all need to laugh more and to find more joy in each day. I’m so grateful that Cole has had this influence on my life. Yes, it’s not what I expected, it wasn’t what I had dreamed, but it is very positive.

Thanks for listening to this podcast. Orange Socks is an initiative of Rise Incorporated, a nonprofit 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.