An Orange Socks Story: Karen- Down Syndrome

Interview by: Gerald Nebeker, President of Orange Socks

Gerald: I am so grateful to Karen, who took the time to have an Orange Socks interview by phone with me about her son, Caleb, who has Down syndrome.

Gerald: Karen, thank you very much for taking the time to speak with me about your son, Caleb. When did you find out that Caleb had Down Syndrome?

Karen: We did not find out until he was born. We were both older when we got pregnant. I was 44, and my husband was 50, and as a result of that, we were referred to a high-risk obstetrician. We went monthly for sonograms, but they never did pick up the fact that he had Down Syndrome, or that he had two heart issues. Which, I guess, was more surprising than the Down Syndrome. We were surprised at first, and here we are 10 years later.

Gerald: Wow, so what have been the greatest challenges that you've experienced with Caleb so far in his life?

Karen: I would have to say just realizing his limitations and how we can bridge that gap into making him the most successful version of himself. Regarding his health, he did have the two heart issues, and that was very scary for us in the beginning. Our daughter was a healthy child, who didn't have any health issues, so those two heart conditions were far scarier than the Down syndrome. He hasn't had surgery on either of those, knock on wood. He had an atrial venosus, an atrial septal defect which has closed on its own, and he also had a ventricle septal defect that is still open. He's monitored for that every two years by a Cardiologist. He has no restrictions on activities, so that's good news. We just try to balance that. He also has hypothyroidism, but that's managed with a pill every morning, so that's not that restrictive of his activity. It was pretty scary in the beginning, really something that took us back, along with the general population's assumptions of what people with disabilities can or can't do, and trying to balance that with his abilities and his strengths to show the world that our folks can do pretty much anything with some accommodations.

Gerald: Tell me about the joys that you've experienced having Caleb in your life.

Karen: Oh, gosh, I don't know where to start. He's absolutely been such a blessing to our lives. Someone asked me just the other day if I could change anything or take away the Down Syndrome, and I said, "Absolutely not!" It has been an amazing ride so far, and we are very excited to see what the future will bring. He has just brought an expanded vision to our living. The world is bigger than what it was previously. We see people in a different light. I think we are more accepting of other people. As you and I agreed, there is this gentleness that he brings to our living that we probably didn't have before, and definitely patience. He just loves life, and he loves every day. He's not afraid of much, so he encourages us to go beyond our comfort level on a lot of different things, and live life to the fullest along with him.

Gerald: That's great. Tell me about the impact he's had on your family, on your immediate family and on extended family, friends and neighbors.

Karen: Well, personally for me, he absolutely changed my life and my work life. I started working in the disability field shortly after he was born, so I am very involved with a number of advocacy groups and parent support groups. That's been 10 years now. Our daughter, who was 17 when he was born, decided to study special education when she was in college, and as a result, she's now a special education teacher. I think our extended family has also been impacted just because they've had to learn along with us the road of disability, and how people can be more included in all aspects of life.

Gerald: That's super. If I were to come to you with either an in utero or post that I had a child with Down Syndrome, what advice would you give me?

Karen: Actually, I get that quite a bit at my work at the Down Syndrome Association. Even today people ask me about that. I've seen people on Instagram who just found out that they've been carrying a child with Down Syndrome, and my advice is to first take a deep breath because I know how scary it is. It's a new world, and you're not used to it. So it can be scary because you really don't know what's ahead. One of the biggest factors is the obstetrician's response, how that doctor encourages you or not, and what advice he or she might offer about meeting with other families who have a child with Down Syndrome, or maybe referring that parent to a local support group or even a national support group. When I was at the Down Syndrome Association, a woman who was carrying a child with Down Syndrome came to one of our social groups, so she got to see firsthand what those kids were doing and how they interacted. She also got to talk with parents. I thought that was really great on her behalf, to look that far ahead and want to know how to raise her child, and to be respectful of their future.

Gerald: That's great. That's super. I'm just wondering, do you have some parting comments, or anything in general, that you'd like to say before we end our conversation?

Karen: I would just like people to open their minds to the possibility of people with disabilities. People with Down Syndrome, people with Autism, or people with any real "disability," and make sure that they are looking at them through the lens of capabilities and abilities instead of disabilities. I think the world has changed some. When Caleb was born 10 years ago, there were few people with disabilities in advertising. We've got some TV shows on now that feature individuals with disabilities, so hopefully the culture is changing to be more accepting. I certainly want Caleb to live in a world where he is asked, "How can I make things easier for you?” or “How can I include you?” We all belong in the world, and we all have a part to play, so we all need to be respectful of that.

Gerald: Very good, thank you so much for taking some time to speak with me. I’m honored that you’d do so.

Karen: Absolutely.