

## **More Alike than Different**

**OpEd for World Down Syndrome Awareness Day 3/21**

**Jennifer Sheran, Mother of Joseph – 8 months old**

Word count: 769

The numbers 3 and 21 will forever have significance for me. It signifies Trisomy 21, the diagnosis my son was given in the hospital six days after he was born. Otherwise known as Down syndrome, Trisomy 21 is a genetic chromosomal disorder for which there is no known cause and no cure.

Like many of you, I had seen people in the community with Down syndrome but had little understanding of the condition. But now, eight months after my son's birth and on the eve of World Down Syndrome Awareness Day, I find myself an advocate for people with Down syndrome and a dedicated cheerleader for my Joey as he strives for each developmental milestone.

While I continue to educate myself about how Down syndrome, I find that I was not alone in my ignorance about the disorder.

As my husband and I learned the news of our son's diagnosis, it became painfully clear that many people – even in the pediatric medical community – still have a lot to learn about Down syndrome.

Our journey began while we were waiting for the tests to come back. Huddled over our son's incubator in the NICU, the well-meaning nurse who was caring for our son informed us that "a lot of people want to adopt children with Down syndrome." While laying out a vision for our son's future, the NICU doctor said, "He may be able to string a few words together." What was already a difficult time for us was made so much worse by their ignorance.

Never very sensitive to labels and terminology, I soon found myself surrounded by all these predetermined labels for the bundle of joy in my arms. Nevertheless, the optimist, as well as the mom, in me chooses to focus on the potential and possibilities that lie ahead for my son and not on what people say he won't be able to do.

Thankfully, parents, teachers and other advocates have traveled this path before me. Where 20 years ago many babies with Down syndrome were institutionalized, now through programs such as Babies Can't Wait, they are given the physical, occupational and speech therapy they may need to ensure they get the best start on life. Thanks to the Individuals with Disabilities Education Act (IDEA), a law ensuring services to children with disabilities, my son will be able to learn in classrooms alongside his peers. Because of research on how people with an extra chromosome best learn, many people with Down syndrome are accomplishing what some might not have thought possible — graduating from high school and even attending postsecondary education programs.

However, we continue to struggle at the state-level for funding for programs such as Babies Can't Wait or Georgia Pre-K. Similarly, millions of federal dollars are being diverted from Down syndrome research to other health or disease research areas, making Down syndrome one of the least-funded research programs at the National

Institutes of Health, even though disorder has a larger impacted population and higher incidence rate.

And perhaps most concerning is that people with conditions like Down syndrome still suffer a social stigma; they are often pre-labeled and marginalized. “When we encounter someone who has special needs, often something in our brain shuts down because we don’t know anything about it. It’s not our world. A switch turns off and we don’t connect with it,” explains Emily Colson, author of *Dancing with Max: A Mother and Son Who Broke Free*.

Just the other day, I was with a group of moms discussing the challenges of educating children at different learning levels. One mom offered, “There should just be special schools for kids with disabilities.” It is sad that in the land of the American dream we might still as a society think it is right to withhold the opportunity to achieve by marginalizing and isolating some of our most courageous citizens.

The truth is people with Down syndrome are more like “average” persons than they are different. They go to school, work, have relationships, enjoy sports and hobbies and contribute to society in many wonderful ways. And they happen to have an extra 21<sup>st</sup> chromosome. For our family, that extra chromosome has meant an extra special boy who has carved in our hearts an overwhelming capacity to hope, love and experience immeasurable joy. I am thankful that after the NICU doctor gave his limited forecast for my son’s future, I did my own research and found that the forecast is actually very sunny indeed. Join me in considering how people with Down syndrome are more like us than different by visiting <http://ndscenter.org/morealike> and pass it on.

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Jennifer Sheran is a mother of three children including an eight-month old son with Down syndrome. She lives in Snellville with her husband Chuck and works at The DeMoss Group, a public relations firm in Buckhead. World Down Syndrome Awareness Day is celebrated on 3/21 in recognition that persons with Down syndrome have a third copy of the twenty-first chromosome. Down syndrome is the world’s most commonly occurring chromosomal condition.